

Sixth Edition

*Hard
Choices
for
Loving
People*

CPR,
Feeding Tubes,
Palliative Care,
Comfort Measures,
and the Patient
with a Serious Illness

By Hank Dunn
Chaplain

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About the Author

Since 1983, Hank Dunn has been ministering to patients at the end of their lives and their families. He served as a nursing home chaplain at Fairfax Nursing Center and as a staff chaplain for the Hospice of Northern Virginia, now Capital Hospice.

Hank is a graduate of the University of Florida and received his Master of Divinity degree from the Southern Baptist Theological Seminary in Louisville, Kentucky. After serving five years as a youth minister at a very traditional church in Macon, Georgia, he moved to the DC area to be a part of the very nontraditional Church of the Saviour. He worked a year as a carpenter and for four years directed an inner city ministry before moving into the chaplaincy in 1983.

He is a past president of the Northern Virginia Chapter of the Alzheimer's Association. He has served on the Ethics Committee at the Reston Hospital Center and the Chaplaincy Advisory Board at the Loudoun Hospital Center. He continues to volunteer as a chaplain at the Loudoun Hospital and at the Loudoun Adult Medical Psychiatric Services. For several years, Chaplain Dunn volunteered at Joseph's House, a home for formerly homeless men and women who are terminally ill. He is also a Volunteer Pastoral Associate at his faith community, Vienna Baptist Church, where he is especially involved in the retreat ministry at the Lost River Retreat Center in West Virginia.

To help him explain end-of-life decisions to patients and families, he wrote a booklet to hand to them so they could reflect on the issues discussed. As an afterthought, he sent the book out to other institutions to see if they would be interested in purchasing it for the people they serve. First published in 1990, *Hard Choices for Loving People* has sold over 3.5 million copies, and is being used in more than 5,000 hospitals, nursing homes, faith communities, and hospice programs nationwide. His second book, *Light in the Shadows: Meditations While Living with a Life-Threatening Illness*, Second Edition, was released in 2005. This is a collection of reflections on the emotional and spiritual concerns at the end of life.

Hank Dunn is a frequent speaker on topics related to the end of life. He enjoys backpacking, kayaking, and hiking.

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Introduction

On the occasion of her 102nd birthday, I visited Mable in her room at the nursing home to ask her the secret to a long life. Since she was a minister's wife, I expected some niceties like "clean living" or "just trust God." But she was too wise for that. "Mable, how do you live to be 102?" I asked. Without hesitation she responded, "Just keep breathing!"

I wish it were so easy. If we want to stay alive, we "just keep breathing." Or when there is no hope of recovery from an illness, we could "just stop breathing." Real life is not so simple for patients who find themselves moving toward the end of a long decline in their health.

Throughout most of our life, medical treatment decisions are quite simple. We get sick. Our doctor prescribes a treatment. Since we can only benefit from the physician's orders, we follow the treatment plan and return to our previous state of health.

Yet as our health declines, medical decisions become more complex. Patients who have multiple medical problems, who are dependent on others for daily care (like nursing home residents), or who have a terminal condition often face difficult treatment choices.

For patients with a serious or long-term chronic illness, some medical treatments offer little benefit. These treatments may be painful or increase the burden of living. This makes healthcare decisions more difficult, because we must constantly weigh possible benefits against possible burdens of a particular treatment plan. Sometimes people conclude that the burdens far outweigh any possible benefit, and they therefore refuse a particular treatment. Others feel that even a small potential benefit is worth the significant burdens.

Today's generations are the first to be faced with making such difficult choices about potentially life-prolonging medical treatments. Modern medical developments like ventilators, feeding tubes, and cardiopulmonary resuscitation (CPR) have improved the odds for some of surviving an accident, heart attack, or stroke.

It is very important that patients and their families discuss the use of life-prolonging medical procedures.

But the declining health of patients with multiple medical problems—or of those with a terminal condition—make the chance of survival much poorer than that of the general public. Therefore, it

is very important that all seriously ill patients and their families discuss the use of life-prolonging medical procedures.

This book is written to provide guidance to patients and their families facing “hard choices” as they receive and participate in healthcare. The goal is to give enough information to help make informed decisions.

The Four Most Common Decisions

Some of the hardest choices about medical care that patients and families must face can be summarized in four questions¹:

1. Shall resuscitation be attempted? (see pages 7–12);
2. Shall artificial nutrition and hydration (a feeding tube) be used? (see pages 13–24);
3. Should a patient be transferred from their place of residence to a hospital? (see pages 37–39); and
4. Is it time to shift the treatment goal from cure to hospice or comfort measures only? (see pages 28–36)

Besides these four more common decisions, some attention will also be given in this book to palliative care, ventilators (breathing machines), dialysis, antibiotics, pacemakers and implanted defibrillators, and pain control. Consideration will be

given for how these treatments affect different patients, including children or those with dementia (for example, Alzheimer's). After a thoughtful reading of these pages, you may want to discuss what is contained here with your family and physician.

Although I draw from medical research and my professional experience with these decisions, I can only make general suggestions about treatment options. I recommend discussing available medical treatments with your physician and other healthcare professionals familiar with your particular case. My experiences may not address the specific circumstances you are facing. All the stories I share are true, though I have changed certain names to protect privacy.

Goals of Medical Care

Before thinking about potentially life-prolonging medical procedures, it's important to establish the goal of medical care.² Ask yourself, “**What outcome can we reasonably expect from medical treatment, given the current condition of the patient?**” After the patient (or the decision maker for the patient) and the medical team agree on this goal, then the medical professionals can recommend ways to achieve that end. Here are the three possible goals of medical care:

1. **Cure.** Almost all healthcare today is focused on preventing and curing disease. We become sick. The physician prescribes a treatment. We are cured.
2. **Stabilization of functioning.** Many diseases cannot be cured, but medical treatment can stabilize the patient and temporarily stop the disease from getting worse. For example, although there is no cure for diabetes, a person can take insulin injections for a lifetime and function fairly well. I have also known several patients whose poorly functioning kidneys made it necessary for them to travel to a local hospital three times a week for dialysis. These treatments can be considered appropriate even though they offer no hope of cure.

I knew a 32-year-old man with muscular dystrophy. He breathed with the help of a mechanical ventilator and used a voice-activated computer. He was an avid sports fan and had a great sense of humor. This patient's treatment could not cure his disease, but he could function at a level acceptable to him.

- 3. Preparing for a comfortable and dignified death.** This is the hospice care or “comfort measures only” approach. Each of the dialysis patients I mentioned before reached a point at which they decided that the treatment no longer offered them an acceptable quality of life, and so it was discontinued. They each died a short time later with appropriate care given to keep them comfortable. Preparing for a comfortable and dignified death is a shift away from the direction of most medical care given today. It is a shift away from most of the medical training our physicians receive. It is also a shift away from the mission of our hospitals, which exist primarily to cure patients.

At times, these goals can be combined. I have seen many people decide to prepare for a comfortable and dignified death in the face of their end-stage cancer, but choose to cure pneumonia with antibiotics. Others in similar circumstances decline even the antibiotics.

Goals of care often change with the patient's condition. I asked the man on the ventilator under what condition he would like it turned off so that he might be allowed to die a natural death. He said, “When I end up like my roommate, who makes no response to anyone.”

One way to find out if a treatment can accomplish a hoped-for outcome is to try it for a little while. Patients can try treatments in an effort to cure or stabilize, and then reassess after a certain period of time (see “time-limited trial,” page 23).

During my first summer as a hospice chaplain, I was reminded once again of the importance of setting goals before deciding on

treatment. We had admitted a new patient on a Friday. By the following Monday, I had two urgent voicemail messages from a nurse and a social worker. The messages went something like this: “Hank, we have a new patient who is very close to dying and her daughter wants everything done to try and save her, including CPR and ventilator support. Can you help?”

The patient was indeed very ill, and it turned out she was within a week of dying regardless of her treatment choices. She was totally dependent on her daughter for her care. She had just been discharged from the hospital after they were able to get her off of a ventilator. However, she still received her nutrition through a feeding tube.

When I got to the home, the patient was in a recliner in the middle of the family room. She could not speak nor lift a hand, although she did listen and seemed to understand what was going on. At the end of my visit, I asked the daughter to follow me out to the car so I could give her a copy of this book. I took the opportunity to try to convince her not to attempt heroic measures on her frail mother.

We spoke for a while, and soon, with tears running down her cheeks, she said, “All I want is for my mother to die peacefully here at home.” I said, “We can help you with that, but it will not involve the rescue squad or putting your mother on machines.”

I left. A few hours later, I received a call from the daughter. She had one question: “How long does it take a person to die if you stop tube feeding?” I told her what my experience had been, and assured her that her mother would be kept comfortable if she were to decide to stop the feedings.

I had not mentioned withdrawing the feeding tube. She had already established the goal herself: “All I want is for my mother to die peacefully here at home.” Once she had the goal in mind, the decision became more clear. She could then entertain the idea that perhaps a feeding tube is not compatible with a peaceful death. In the end, she did not have to make the call. Her mother died peacefully at home three days later.

What really makes these decisions “hard choices” has little to do with the medical, legal, ethical, or moral aspects of the decision process. The real struggles are emotional and spiritual.

In my more than three decades as a chaplain at a nursing home, a hospice, and a hospital, I have been at the bedsides of many seriously ill patients. I have discussed these treatment choices with their families in the halls outside the patients’ rooms. This first-hand experience adds as much value to the content of this book as the medical research upon which it is based.

I am convinced that what really makes these decisions “hard choices” has little to do with the medical, legal, ethical, or moral aspects of the decision process. The real struggles are emotional and spiritual. People wrestle with letting go and letting be. These are decisions of the heart, not just the head.

In Chapter Five of this book, I give my personal views on these decisions, especially on the spiritual and emotional struggles within (see page 54).

Citations to the research related to the topics discussed in this book are listed in the endnotes, pages 77–80. For a full listing of the endnotes and additional references, go to **www.hankdunn.com/references**.

Chapter One:

CPR—Cardiopulmonary Resuscitation

This chapter will answer the following questions:

- How successful are efforts to restart a heart?
- Can we know ahead of time which patients likely will not be revived by resuscitation efforts?
- How do patients let their wishes be known if they choose not to have resuscitation efforts?

During the 1960s, medical researchers developed a method of rescuing victims of sudden death. Known as cardiopulmonary resuscitation (CPR), this method is used when a person's heart and/or breathing stops. Traditionally, the rescuer repeatedly applies force to the victim's chest with the hands to compress the heart, and breathes into the patient's mouth to fill the lungs with air. These days, the rescue breaths are considered optional. Thousands of lives are saved each year with CPR.

CPR was originally intended to be used for situations where death was accidental, such as drowning or electrical shock, or when an otherwise healthy person experienced a heart attack. Some of the early guidelines even said that there were certain cases when CPR should not be used: **“CPR is not indicated in certain situations, such as cases of terminal irreversible illness when death is not unexpected. . . . Resuscitation in these circumstances may represent a positive violation of a person's right to die with dignity.”**³ Today, in hospitals, nursing homes, and residential care facilities, CPR has become standard practice on all patients who experience heart or breathing failure, except for those with orders restricting its use.

Survival Rates with CPR

If a hospital patient's heart stops, a "code" is called and a special team responds. Treatment may include CPR, electrical shocks to the heart, injection of medications, and the use of a ventilator. Approximately 35% of hospital patients whose heart or breathing stops⁴ and 3% of nursing home residents in a similar condition⁵ receive resuscitation attempts.

Approximately 17% of all hospital patients who receive CPR survive to be discharged.⁶ Although it is hard to know exactly who will survive, we do know three categories of patients who most likely will NOT survive.

Patients with the least chance of survival (usually less than 2 percent survive):

- Those who have more than one or two serious medical conditions⁷
- Those who are dependent on others for their care, or who live in a long-term care facility like a nursing home⁸
- Those who have a terminal disease⁷

The Burdens of CPR

Like most medical procedures, CPR has potential burdens. A frail patient may have their ribs broken or their lungs/spleen punctured because of the necessary force applied during CPR. If the patient has been without oxygen for too long, there will be brain damage if they are revived. This brain injury can range from subtle changes in intellect and personality all the way to permanent unconsciousness, called a "persistent vegetative state"⁹ (see page 14).

Because of the chain of events put into motion when CPR is begun, a person could be placed on a breathing machine even though he or she might not have wanted it. For many patients, this risk of having severe brain injury and being "kept alive by machines" is a very serious burden. CPR also severely reduces the possibility of a peaceful death.

CPR in Nursing Homes, Assisted Living, and Memory Care

Residential care homes have professionals on duty trained to administer CPR. If CPR is begun, the staff will call 911 and the rescue squad will arrive. Once on the scene, the paramedics take over the care of the resident. They will then continue CPR until the patient has been transported to the nearest emergency room, where the staff will do everything in their power to bring the patient back to life. Measures could include continuing CPR, electrical shock, or the injection of medications. Once in the emergency room, patients may be connected to machines to keep them breathing through a tube inserted in the mouth and down the windpipe.

Calling 911 means everything possible will be done to resuscitate the patient. It is good for us to know that the rescue squads in our communities will respond as quickly and as aggressively as possible to save lives. However, the research on CPR in nursing homes indicates that less than 2% of patients receiving resuscitation attempts survive.⁸

Why does CPR offer so little hope of medical benefit for nursing home residents? Most of the characteristics that point to a poor prognosis for CPR survival are common in nursing home residents, who are often frail or debilitated. By definition, residents do not live independently because of their generally failing health. Most also have multiple medical problems.

Some people ask, “Can we just try CPR at the residential care home and not transfer a resident to the emergency room for more aggressive treatment?” This is not standard procedure, and for good reason. The professionals at a care home want as much support as possible if they are trying to revive a resident. That support can come only from a rescue squad, and only the advanced medical team at an emergency room can determine whether all attempts at revival have failed.

Remember, once the chain of events is set in motion by beginning CPR, it is very difficult to stop until every procedure

has been attempted. If CPR is successful, the patient will then need to stay in the hospital for follow-up care.

CPR and the Patient with a Serious Illness

There are some patients who may benefit from CPR. An open, honest discussion with a physician will help any patient assess the possible benefit. But those who find themselves among the

Because of the chain of events put into motion when CPR is begun, a person could be placed on a breathing machine even though he or she might not have wanted it.

“patients with the least chance of survival” group will find the medical benefits from CPR are minimal.

Again, this would include patients with multiple serious medical problems, those who have a terminal disease, or those who are dependent on others for care, including long-term residents of nursing homes, assisted living facilities, and memory care facilities. In deciding whether to

accept or reject CPR, one must weigh the facts. **Once a patient with one of the above conditions has a cardiac or respiratory arrest, there is only a small possibility of having the heart restarted. There is even less chance of surviving the subsequent hospitalization.**

The frailty that goes with the worsened medical condition common among these patients contributes to this poor outlook for survival. Even if the patient survives the event that required CPR, the chances of long-term survival are slim. The individual’s condition will most likely be much worse than before. Given these facts, many people choose not to have CPR used as a medical treatment for seriously ill patients. Others feel that CPR offers some hope of survival and that every effort should be made to save a person’s life, no matter the medical condition or prognosis.

CPR and Children

Age has not been shown to be a factor in the success of CPR. Some of the same conditions that make resuscitation attempts unsuccessful in the general population apply to children as well. Children with multiple organ system failure or those in the terminal phase of a disease have little chance of surviving CPR.

What makes the decision to withhold resuscitation attempts on these little ones so difficult is the overwhelming sense of loss for the parents and for the medical staff. Parents may feel like making the choice to say “do not resuscitate” symbolizes their lost hopes for the future of their child. The physician and other healthcare workers can help sort out the medical side of this decision. The more difficult part is letting go and letting be.

CPR Is the Standard Order

Upon admission to a nursing home, an assisted living facility, memory care facility, or hospital, it is assumed that every patient whose heart stops will receive CPR. This presumption *for* CPR is reasonable, since any delay in beginning the procedure greatly reduces the chances for success.

This means that if a person would rather not have resuscitation attempts, a doctor must write an order restricting its use. This order goes by many different names: DNR (do not resuscitate), DNAR (do not attempt resuscitation), AND (allow natural death), No Code, or No CPR. This order must be given by the physician, and often the family or the patient must request it. In most cases, the staff or physician will not make a DNR decision without a discussion with the patient or family, no matter how seriously ill a patient may be.

Also keep in mind that when 911 is called, the rescue squad will automatically attempt CPR on any person whose heart or breathing stops. Many states provide a document or bracelet to show the emergency personnel if the patient would not want to receive resuscitation attempts. Sometimes called an “Out-of-

Hospital DNR Order,” this document can allow a family to feel confident in calling the rescue squad for help. They can know they will receive comfort care and supportive help for the patient while not running the risk of attempts at resuscitation or being “hooked up to machines.”

Chapter One Summary:

- About 17% of patients in hospitals who have CPR attempts survive to be discharged.
- In most cases, patients with multiple serious medical problems, with a terminal illness, or who cannot live independently survive CPR less than 2% of the time.
- Possible burdens of “successful” CPR include fractured ribs, punctured lungs, brain damage, depression, never regaining consciousness, risk of the patient being connected to machines for his or her remaining days, and reduced possibility of a peaceful death.
- Patients, or those making decisions for them, may request from the physician an order not to attempt resuscitation.

Chapter Two

Feeding Tubes—Artificial Nutrition and Hydration

This chapter will answer the following questions:

- What are some of the benefits and hazards of using feeding tubes?
- What are some of the advantages of dying without the use of artificial feeding or IVs?
- What is a time-limited trial?

When a patient can no longer take food or fluid by mouth, a feeding tube can sometimes be used instead. Liquid nutritional supplements, water, and medications can be poured into the tube or pumped in by way of a mechanical device. Tubes usually come in one of two types:

- **The nasogastric (NG) tube** is inserted through the nose, down the esophagus, and into the stomach.
- **The gastrostomy is a tube** inserted surgically through the skin into the stomach wall. Sometimes this method is called a PEG* tube, or a G-tube.

There are other types of tubes, such as jejunal tubes (J-tubes). These tubes bypass the stomach and are inserted directly into the small intestine. There is also the less common TPN**, when a catheter or needle is inserted in a vein, often in the chest, and a liquid containing nutrients is pumped directly into the blood stream, bypassing the entire digestive system.

* percutaneous endoscopic gastrostomy

** total parenteral nutrition

The Benefits of Artificial Feeding

Feeding tubes have proved beneficial to thousands of patients. Many people, such as some stroke patients, need the help of a feeding tube for a short period before going back to eating by mouth. Others live with a gastrostomy tube and enjoy reading, watching television, or visiting with their families.

I had one patient who had lost the ability to swallow due to throat cancer and had a feeding tube. He lived alone and was hampered in his ability to care for himself because of emphysema. I asked him once how he felt about the feeding tube. "Great!" he said. "I don't have to go grocery shopping. I don't have any pots and pans to wash. And I can stay in my own home." Clearly he felt he benefited from the feeding tube.

Artificial Feeding in Non-Responsive Patients

Often a patient with a serious or long-term chronic illness never regains the ability to eat or drink. Some people survive for years on a feeding tube. Karen Ann Quinlan, although disconnected from a respirator, lived unconscious for more than 10 years receiving nutrition and hydration through a feeding tube. Rita Greene, who made no response to any stimuli, lived for 48 years with the aid of a feeding tube.

Patients who make no sort of purposeful response to their surroundings have been described as either permanently unconscious or in a persistent vegetative state (PVS).¹⁰ Most often these patients suffered brain damage from an interruption of the flow of blood to the brain. All their vital body functions operate without the aid of machinery with only the artificially supplied nutrition and hydration needed to keep them alive. Frequently they are young people left in this condition after an automobile or sporting accident. Sometimes, people end up in this non-responsive condition after "successful" CPR.

As one might expect, a variety of opinions are expressed on whether or not to artificially feed and/or hydrate hopelessly ill

or dying patients. There is a wealth of research and opinions on the use of artificial nutrition and hydration with the goal of discovering whether or not using it is helpful to the patient or whether it does harm.

Often the standard medical practice is to start tube feeding for any patient who can no longer take in enough food or water by mouth. A patient may receive a feeding tube unless the patient or family makes a conscious choice not to do so.

The Burdens of Artificial Feeding

Feeding tubes are not without risk. Pneumonia can develop if the tube becomes displaced or if regurgitated fluid (vomit) enters the lungs.¹¹ Ulcers and infections can also result from a feeding tube.¹² A patient who repeatedly removes the tube will probably need to be restrained or sedated. The immobility of most of these patients makes them prime candidates for bedsores and stiff limbs.¹³ Furthermore, patients can be more isolated with artificial feeding than hand feeding because they lose the personal interaction of someone sitting with them and feeding them three times a day.

A stroke patient with an artificial feeding tube came to our nursing home from the hospital. She made little response to caregivers and to her family. The family had agreed they would try the feeding tube for a year and if there was no improvement, they would stop the treatment and let her die.

At the end of the year, along with withdrawing the artificial feeding, a speech therapist worked with the patient to try to help her eat again by mouth. Not only did she live for another year without the artificial feeding, but her whole personality changed. She was more interactive, smiled more, and generally seemed to be in better health. I was able to observe this patient with and without artificial feeding, and the difference was striking. I know this is just one case, but I am convinced that the personal connection with the nurse or aide three times daily, plus the pleasurable stimulation of eating, changed this woman's life.

The Case for Artificial Feeding in Most Circumstances

Some say that a feeding tube should be used in most cases because food and water are forms of basic care that should not be denied to anyone, no matter what their prognosis is for recovery. They might also say that feeding tubes should be used in most cases because they feel the benefits outweigh the burdens. Those who advocate such a position often allow that an adult who is able to make decisions can refuse any medical treatment, including artificial nutrition and hydration.

Those who advocate for using a feeding tube under most circumstances might characterize the act of not providing nutrition and hydration artificially as “starvation.” Indeed, anyone who does not receive food and water will die, though their condition would more accurately be described as “dehydrated” rather than “malnourished”^{14,15} (see page 18).

They also might describe the insertion of a feeding tube as just providing “basic food and water” like hand feeding and, therefore, not a medical intervention.¹⁶ Additionally, since the patient will die in a short time if a feeding tube is removed, they may argue that the intent of those removing the tube is to end the life of the patient, which is clearly against the very nature of medicine.¹⁷

The Case against Artificial Feeding in Some Circumstances

Many people feel that the use of feeding tubes in some cases may cause excessive burdens in the patient or may provide insufficient benefits, and therefore they are not obligated to use them in all cases. They might make the argument that artificial feeding of terminally ill persons or those in an irreversible coma is more of a burden than a benefit to the patient.

We are not obligated to preserve our lives at all costs. People who choose not to have life prolonged on a mechanical ventilator are, in a way, “denied” air. Some consider withholding or

withdrawing feeding tubes to be similar to taking someone off of a ventilator. Feeding tubes become morally optional when they are no longer beneficial for the patient or would cause clinical burdens or significant physical discomfort.

People who advocate the removal of feeding tubes in some circumstances might see the inability to take in food and water by mouth as a terminal medical condition. To withhold or withdraw artificial feeding is to let death from the underlying condition occur naturally.^{14,15} When a person dies after the withholding of artificial food and fluids, the death is from the condition or disease that made the patient unable to eat, not from the removal of artificial feeding. Therefore, nothing is being introduced to “kill” the patient, but the natural process of dying is being allowed to progress.¹⁸ Choosing not to force-feed a person is choosing not to prolong the dying process.

Common medical practice says that a doctor can ethically withdraw all means of life-prolonging medical treatment, including food and water, from a patient in an irreversible coma. Courts in many states and the U.S. Supreme Court have upheld this view and allowed the withdrawal of feeding tubes. There is a consensus among state legislatures and in medical literature viewing artificial feeding as a medical procedure that may be withdrawn.¹⁹

Intravenous (IV) Artificial Hydration

A common method of artificial hydration, especially in a hospital, is the IV line. A patient can receive fluids and medications through a needle or catheter (plastic tube) in the arm. The process of inserting the IV can be uncomfortable. The patient may need to have the point of insertion changed frequently if the IV does not work, or every three to five days to prevent infection or irritation. If patients pull at the tubes, their hands may need to be tied down. For most patients, these are appropriate and acceptable burdens.

Although this chapter mostly addresses the use of feeding

tubes, IVs are related. When used to hydrate a dying patient, IVs are included in the discussion of artificial feeding tubes because they also supply hydration artificially. Patients and families should frequently reconsider whether the use of IVs is appropriate, especially as the time of death approaches. Much of what we know about withholding artificial hydration at the end of life has been discovered as caregivers observed patients dying with and without the use of IV fluids.

The benefits of NOT using artificial hydration (via an IV or a feeding tube) in a dying patient:

- Less fluid in the lungs and less congestion, making breathing easier
- Less fluid in the throat and less need for suctioning
- Less pressure around tumors and less pain
- Less urination, less need to move the patient to change the bed linens, and less risk of bedsores
- Less fluid retained in the patient's hands, feet, and body (forcing liquids into a person whose body is shutting down can create an uncomfortable buildup of fluid)
- Natural pain-relieving chemicals are released as the body dehydrates, causing a sense of well-being sometimes described as "mild euphoria" (this state also suppresses appetite)²⁰

Does Withholding or Withdrawing Artificial Feeding Cause a Painful Death?

To say that withholding or withdrawing artificial nutrition and hydration is "starvation" (and therefore perhaps causing suffering) is inaccurate. Whatever pain or discomfort is associated with malnutrition (i.e., starvation) is not relevant here, because a patient will be affected by dehydration long before suffering any ill effects from the lack of nutritional support.¹⁵

Therefore, pain treatments must address any pain a dehydrating patient may suffer as well as addressing the relief of acute pain that may be the result of another condition, such as cancer.

A genuine concern on everyone's part is pain control. If a patient is allowed to die by forgoing artificial feeding, can pain and discomfort be held to a minimum? The answer is "yes."

Patients who have had brain damage and no longer respond to their environment "cannot experience pain and suffering."¹⁰ For patients who have some responses, there are ways to alleviate acute pain without the use of artificial feeding tubes or IV hydration.

Beyond the issue of acute pain is the question of whether dying of dehydration causes any other unnecessary pain or unusual suffering. **The medical evidence is quite clear that dehydration in the end stage of a terminal illness is a very natural and compassionate way to die.**²¹

The only uncomfortable symptoms of dehydration are a dry mouth and a sense of thirst, both of which can be alleviated with good mouth care and ice chips or sips of water but are not necessarily relieved by artificial hydration.

No matter what the treatment choice regarding feeding tubes, **comfort care and freedom from pain are essential goals of any medical team.** Just because extraordinary or heroic measures have been withheld or withdrawn does not mean that routine nursing care and comfort care are withheld. A patient will always receive pain medication, oxygen, or any other treatment deemed necessary to ensure as much comfort as possible.

The Difference Between Withholding and Withdrawing

Imagine how emotionally difficult it would be to withdraw a feeding tube from a person who has been kept alive through artificial means for several months or years. For a family and physician to change the treatment plan like this requires a change in perspective. A person has been living with a feeding tube and now the decision has been made to allow that person to die. It is not impossible, emotionally, to come to this point of withdrawing treatment, but it is more difficult than withholding

the artificial feeding in the first place.

From moral, ethical, medical, and most religious viewpoints there is no difference between withholding and withdrawing. Emotionally, there is a world of difference. And as much as we might like to think physicians do not make decisions and recommendations based on emotion,

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it is just as difficult for them to suggest or accept a change from using the tube to withdrawing.

A family I once knew wanted to withdraw artificial feeding from the patient, and the physician told me, "I would have had no problem not starting the treatment in the first place but I cannot order the withdrawal."

There is nothing in law, medicine, ethics, or morality to justify such a stance. If withholding treatment would have been acceptable earlier, then only emotion could now require its continuation.²²

The difficulty of making the decision to withdraw treatment makes it very important to think through and discuss these issues long before a crisis comes. **If a patient or family does not want to use artificial feeding, it is much better not to begin the feeding at all. But if it is begun, artificial feeding can be withdrawn at a later date.**

Artificial Feeding and the Dementia Patient

Alzheimer's disease and other forms of dementia are characterized by the deterioration of the person over a number of years. In earlier stages of the disease, it may be helpful to the patient to use a feeding tube as a temporary measure in the event of a decline in appetite or weight loss. The hope is that the patient will eventually be able to take in enough food and fluid by mouth to be able to discontinue the tube.