Hard Choices For Loving People

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 5 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 4 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 3,000,000 copies, and is being used in more than 6,000 hospitals, nursing homes, faith communities, and hospice programs nationwide. His second booklet, 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.
On the occasion of her 102nd birthday, I went into Mable’s room at the nursing home to ask her the secret to a long life. I expected some niceties like “clean living” or “just trust God,” since she was a minister’s wife. But she was too wise for that. “Mable, how do you live to be 102?” Without hesitation she responded, “Just keep breathing!” I wish it were so simple. 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 in hospitals, nursing homes, or hospice programs, or for those 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.

The difficulty arises from the fact that for patients with a life-threatening illness, or even a long-term chronic condition, some medical treatments offer little benefit. At the same time, these treatments may be painful or increase the burden
of living. As we make decisions, 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 therefore refuse a particular treatment. Others feel that even a small potential benefit is worth the significant burdens.

The generations alive today are the first generations faced with making such difficult choices about potentially life-prolonging medical decisions. Modern medical developments like ventilators, feeding tubes, and cardiopulmonary resuscitation (CPR) have improved a few people’s chances of surviving an accident, heart attack, or stroke. But the declining health of patients with multiple medical problems—and those with a terminal condition—make their outlook for survival much poorer than that of the general public. Therefore, it is very important that all patients with life-threatening illnesses and their families discuss the use of life-prolonging medical procedures.

The Four Most Common Decisions

This booklet is written to provide guidance to patients and their families who must face the “hard choices” as they receive and participate in healthcare. The “hard choices” are found in four questions that require treatment decisions\(^1\) (1) Shall resuscitation be attempted? (pages 11-16); (2) Shall artificial nutrition and hydration be utilized? (pages 17-28); (3) Should a nursing home resident or someone ill at home be hospitalized? (pages 39-41); and (4) Is it time to shift the treatment goal from cure to hospice or comfort care only? (pages 29-38). Besides these four more common decisions, some attention will also be given to ventilators (breathing machines) (pages 41-43), dialysis (pages 43-44), antibiotics (pages 44-45) and pain control (pages 45-46). Throughout this book, consideration will be given for how these treatments affect patients who are children or patients 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. The goal of this booklet is to give you enough information to help you make informed decisions.

Although I draw from my professional experience with these decisions, and I refer often to the medical research, I can only make general suggestions of treatment options one might consider. I recommend discussing medical treatments with your physician and other healthcare professionals familiar with your particular case. I can write only of my experiences with specific medical cases, and they may or may not be similar to the circumstances you are facing. All the stories I share are true, but, at times, I have changed names to protect privacy.

Goals of Medical Care

To begin thinking about potentially life-prolonging medical procedures it is first necessary to establish the intended goal of medical care. The question is, “What outcome can we reasonably expect from medical treatment, given the current condition of the patient?” After the patient (or the decisionmaker for the patient) and the medical team agree on a 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 health care today is directed toward the prevention or cure of diseases. We become sick. The physician prescribes a treatment. We are cured.

2. **Stabilization of functioning.** Many disease processes cannot be cured, but medical treatment can stabilize the functioning of a patient or, in other words, temporarily stop the disease from getting worse. We have no cure for diabetes, but a person can take insulin injections for a lifetime and function fairly well. I knew a 32-year-old man with muscular dystro-
phy who breathed with the help of a mechanical ventilator. He used his voice-activated computer, was an avid sports fan, and had a great sense of humor. His treatment did not offer a cure, but he could function at a level acceptable to him. I have 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.

3. Preparing for a comfortable and dignified death. This is the hospice, “comfort care only” or palliative care approach. Each of those same dialysis patients I just mentioned at one point 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 in the focus and goals away from the direction of much of medical treatment 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 actually be combined. I have seen many people adopt a stance of “preparing 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 often change as the patient’s condition changes. 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 room-mate, 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. And one
can try treatments for a period of time in an effort to cure or stabilize using what is called a “time-limited trial” and then reassess at the end of the trial (see page 27).

My first summer as a hospice chaplain I was reminded once again of the importance of setting goals first. We had admitted a new patient on a Friday. By the next Monday I had two urgent phone calls on my voice mail from a nurse and a social worker. They 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 indeed was 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 a ventilator. However, she still received her nutrition through a feeding tube.

When I got to the home, the patient was in a recliner chair in the middle of the family room. She could not speak or 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 Hard Choices. 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

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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 artificial feeding?” I told her what my experience had been and assured her that we would keep her mother comfortable if she were to decide to stop the feedings. I had not brought up the thought of withdrawing the feeding tube. She had established the goal—“All I want is for my mother to die peacefully here at home.” Then she could entertain the idea that perhaps a feeding tube is not compatible with a peaceful death. She did not have to make that decision because her mother did die peacefully at home three days later. Once she had the goal in mind, she could allow a peaceful death.

After establishing the goal, then the specifics of the treatments outlined in this booklet can be addressed.

In my nearly three decades as a nursing home, hospice and hospital chaplain, I have been at the bedsides of very ill patients, and I have discussed these choices with their families in the hall outside the patient’s room. The content of this booklet comes not only from research but also from first-hand experience. 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 a final chapter I give my view on these decisions, especially on the spiritual and emotional struggles within.
Chapter One

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 are most likely not to be revived by resuscitation efforts?
- How do patients let their wishes be known if they choose not to have resuscitation efforts?

During the 1960s, researchers developed a method of rescuing victims of “sudden death” called cardiopulmonary resuscitation (CPR). Basically, CPR is used when a person’s heart and/or breathing stops. The rescuer applies force to the chest with the hands, thus compressing the heart, and breathes in the patient’s mouth, filling the lungs with air. Thousands of lives are saved each year with CPR.

Originally, CPR was 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 went on to say 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.”

Today, in both hospitals and nursing homes, CPR has become standard procedure 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 shock to the heart, injection of medications, and the use of a ventilator. Approximately 35 percent of hospital patients whose heart or breathing stops and 3 percent of nursing home residents in a similar condition receive resuscitation attempts.

Medical researchers reviewed 113 studies on the use of CPR in hospitals conducted over a 33-year period. They found that of the 26,095 patients who received resuscitation attempts, 3,968 or 15.2 percent survived to be discharged from the hospital. Over the years these survival rates have remained the same.

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

• those who have more than one or two medical problems;
• those who do not live independently or, in other words, are dependent on others for their care or live in a long-term care facility like a nursing home; and
• those who have a terminal disease.

CPR in Nursing Homes

Nursing 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 ventilators. Once in the emergency room, patients may be connected to mechanical
devices 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. We, as a community, need to know that the rescue squad will respond as quickly and as aggressively as possible to save lives.

The research on CPR in the nursing home indicates only 0-2 percent of the patients receiving resuscitation attempts survive. Why does CPR offer so little hope of medical benefit for the frail, debilitated nursing home resident? Most of the characteristics that point to a poor prognosis for the survival in hospital patients are common in nursing home residents.¹³-¹⁶ By definition, residents do not live independently because of their generally failing health. Most have multiple medical problems.

Some people ask, “Can we just try CPR at the nursing home and not transfer a resident to the emergency room, where they do more aggressive treatment?” This is not standard procedure and for good reason. The professionals at a nursing 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 reviving have failed. Once the chain of events is set in motion, it is very difficult to stop until every procedure has been attempted. If successfully revived, the patient will then need to be in the hospital for the follow-up care.

**Burdens of CPR**

Like most medical procedures, CPR does have some burdens. A frail patient’s ribs could be broken and a lung or spleen punctured because of the necessary force applied during CPR. If too much time has elapsed...
since the patient has been without oxygen, there will be brain damage. The brain injury can range from subtle changes in intellect and personality all the way to permanent unconsciousness (“persistent vegetative state”). 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 prolonged survival “on machines” with severe brain injury is a very serious burden. Also, CPR severely reduces the possibility of a peaceful death.

CPR and the Patient with a Life-Threatening Illness

Some patients may benefit from CPR. A frank discussion with a physician will help any patient assess the possible benefit.

But those who find themselves among the “patients with the least chance of survival” group will find the medical benefits from CPR are minimal. Again, this would include (1) patients with multiple medical problems, (2) those who have a terminal disease, or (3) those who are dependent on others for care, including long-term nursing home residents. In deciding whether to accept or reject CPR, one must weigh the facts. Once a patient with one of these conditions has a cardiac or respiratory arrest, there is only the smallest of possibilities of having the heart restarted and almost no 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 and 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. 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 with 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. 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. For a parent to say “do not resuscitate” symbolizes the lost future of the child and lost hopes of the parents. The physician and other healthcare workers can help sort out the “medical side” of this decision. The more difficult part is letting go.

**CPR Is the Standard Order**

Upon admission to a nursing home 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. 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: “No Code,” “No CPR,” “DNR” (do not resuscitate), “DNAR” (do not attempt resuscitation) or “AND” (allow natural death). This order must be given by the physician, and often the
family or the patient must request it. In most cases the staff or physicians will not make a DNR decision without a discussion with the patient or family, no matter how seriously ill a patient may be.

It is also assumed when 911 is called that the rescue squad will try 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 paper 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.”

**Summary:**

About 15 percent of patients in hospitals who have CPR attempts survive to be discharged.

Patients with multiple medical problems, with a terminal illness, or who cannot live independently survive CPR less than 2 percent of the time.

Possible burdens of “successful” CPR include the following: fractured ribs and punctured lungs, brain damage, depression, never regaining consciousness, risk of patient’s remaining days connected to machines, 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.
When a patient can no longer take food or fluid by mouth, a feeding tube can sometimes be used to overcome this disability. 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. Liquid nutritional supplements, water, and medications can be poured into the tube or pumped in by way of a mechanical device. Sometimes this method is called a PEG* tube. 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 digestive system.

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

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*percutaneous endoscopic gastrostomy.
**total parenteral nutrition
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. He said, “Great! 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.

Often, however, a patient with a life-threatening 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.¹⁸

Patients who make no sort of purposeful response to their surroundings have been variously described as permanently unconscious patients or patients in a persistent (or permanent) vegetative state (PVS).¹⁹,²⁰ 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 hydration and nutrition needed to keep them alive. Frequently they are young people left in this condition after an automobile or sporting accident.

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 hydration and nutrition with Feeding tubes have proved beneficial to thousands of patients.
the goal of discovering whether or not using it is helpful to the patient or whether it does harm.²¹-⁴¹

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.

**Intravenous (IV) Artificial Hydration**

A common method of artificial hydration, especially in a hospital, is the IV line. Through a needle or plastic tube (catheter) in the arm, a patient can receive fluids and medications. The process of inserting the IV can be uncomfortable. The patient may have to have the point of insertion changed frequently if the IV does not work, or if 3-5 days have elapsed, 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 both 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 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. Ulcers and infections can also result from a feeding tube. A patient who repeatedly removes the tube will probably need to be restrained by tied hands or sedation. The immobility of most of these patients makes them prime candidates for bedsores and a stiffening of the limbs from lack of movement.
Furthermore, patients can be more isolated with artificial feeding than hand feeding because they lose the personal interaction of someone sitting 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 some response to those who gave her care 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 know this is just one case, but we were able to observe her with and without artificial feeding. I am convinced that the personal connection with a nurse or aide three times a day, plus just the pleasurable stimulation of eating, changed this woman’s life.42

The Case for Artificial Feeding in All Circumstances

Some say that no matter what the prognosis for recovery, a feeding tube should always be used because food and water are basic human rights that should not be denied to anyone. Those who advocate such a position often allow that an adult who is able to make decisions can refuse any medical treatment, including artificial hydration and nutrition.

Those who advocate using a feeding tube under all circumstances often characterize the act of not providing hydration and nutrition artificially as “starvation.” Indeed, anyone who does not receive food and water will die (though their condition would more accurately be described as “de-