

# Understanding Living Wills and End of Life Care

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Living wills and advance directives can be very confusing for most people. Even medical and legal professionals often have difficulty making decisions about what they would want done if they or a loved one became seriously ill. The intent of this chapter is to provide you with a reference that will guide you when you are making these decisions. I will provide you with some real life scenarios and define the terminology that is commonly used in living wills and advance directives. This chapter is an excerpt from my book “Before the Pearly Gates.”

Please be aware that the opinions expressed here are my own opinions based on my experience. Nothing written here should be construed as legal or medical advice. Please consult your attorney and personal physician before applying anything you learn here to your own situation. The stories presented here are true or based on real cases, but the names have been changed to protect the privacy of the people involved.

## **Joan**

Joan sat before me in the ICU bed. She was breathing very rapidly. Her lips were turning blue and she was about to pass out. The oxygen saturation on the monitor read 64%. I could hear the anesthesiologist running towards us. “Thank God” I thought. In a few minutes, Joan would have an endotracheal tube inserted into her windpipe and the respirator machine would do the breathing for her. She would not have to struggle so hard to breathe. She could finally rest and let the antibiotics start working their magic on the terrible infection that was incapacitating her lungs.

I turned to her son who was standing beside me. He had his hand in his pocket and he looked very nervous. “It’s going to be alright.” I told him. “She has an excellent chance of making it through this.” He did not look convinced. Something was really bothering him and it was not just the fact that his mother was struggling to breathe.

Finally, he pulled a piece of paper from his pocket and handed it to me. “I found this in her drawer this morning, while I was looking for her insurance cards,” he said. It was a living will. It looked like one of those fill in the blank, do it yourself forms that I had seen plenty of times before.

“Oh sure,” I said to the son, and quickly glanced through it. “Don’t worry, I told him, this will only apply if the situation becomes hopeless or if she is permanently mentally incapacitated.” “Read the last page.” He said.

In capital letters, Joan had added an addendum to the standard living will:

“I WANT TO BE DNR. I DO NOT WANT TO BE PLACED ON A RESPIRATOR, I DO NOT WANT A FEEDING TUBE, I DO NOT WANT CPR, I DO NOT WANT DIALYSIS. IF I AM CRITICALLY ILL, I WISH TO BE KEPT COMFORTABLE. I WANT MAXIMUM COMFORT MEASURES AND I DO NOT WANT TO BE RECUSITATED IN ANY WAY.”

Immediately, my heart sank. Joan was indeed critically ill but she did not have a terminal condition. She had an excellent chance of recovering from her pneumonia. She just needed a few days on the respirator to recover from her pneumonia. “Why would she put this on her living will?” I asked her son, extremely puzzled and disturbed.

“Her sister died of cancer a couple years ago and she really suffered in the last days. They had her on a respirator and even gave her dialysis.” He explained. “After seeing what happened to her sister, she said ‘I don’t ever want to go through what she went through.’ I think that’s when she went and had this living will made. I know it is notarized, but she did not have a lawyer draw this up so it’s not valid, right?” her son asked hopefully.

“Actually, it is valid.” I responded. “A living will can be written on a napkin. As long as it represents the wishes of the patient made while she was of sound mind, I am obligated to honor it.” For a brief moment, I wanted to tell him to go put it back and say he never saw it. How could I allow this woman to die when I knew that she had a really good chance of pulling through? I had to make a decision quickly. The anesthesiologist was already getting his instruments out of his bag and sizing up her neck to decide what size ET tube to insert.

“Wait”! I said, holding up the document. I called the Intensive Care director over to look at the papers. I was hoping he would say something like “I’m in charge of the ICU. It is obvious she did not mean for the living will to apply in this situation. Save her life for God’s sake”! I was not so lucky. He looked at the addendum she had written and said. “We have to honor this. If we don’t, we can be charged with assault and battery”. He was right of course, but in my heart I knew that this was not what she had meant when she drew up the document. I just could not let her die right now because of a technicality.

I met Joan only a few days prior to her hospitalization. She asked me to take her on as a patient because I make house calls. She had not seen her doctor in years and she hated the hospital. She had refused to be hospitalized and wanted to be treated at home. I knew that her pneumonia was serious so I had convinced her to go to the hospital. She finally agreed but she took two days to get there. By the time she arrived in the emergency room, she was barely able to breathe. We brought her immediately up to the intensive care unit because we correctly predicted that she would need respiratory support to get her over this pneumonia. She had mentioned she had a living will when I saw her at home, but she had said she did not know where it was. She did make her wishes clear that she did not want to be kept alive in a persistent vegetative state. However, she did not mention the addendum she had written on the living will.

I did not know her long enough to really know what her true wishes were. Did she write that addendum into her living will without realizing what she was doing, or was she really ready to die as soon as any illness would take her? She did have moderate emphysema and some arthritis, but she seemed to have a decent quality of life. She certainly did not have any terminal disease or chronic suffering that would make a premature death a blessing.

I knew that if I did not honor her living will, she could sue me and even press charges against me. If I followed her written directive and let her die, the family could try to sue or bring charges, but it would not hold up in court. Joan had made this living will to make sure that her wishes got carried out regardless of what her family or anyone else wanted. The courts understand that this is why people make living wills and they would never fault me for honoring someone’s wishes.

Joan was almost unconscious now, and try as I might, I could not get her to tell me what to do. “Do you want to live?” I kept asking her. “Do you want us to save you?” Joan could not answer. “Should we push some Morphine?” A nurse asked.

At that moment I made a decision that I could have regretted for the rest of my life. I knew in my heart that she had not meant to die like this. “She told me the other day that she *would* want to be resuscitated for a reversible condition,” I lied.

The anesthesiologist took the cue and immediately inserted the ET tube and started “bagging” her. Her oxygen saturation started coming up, and when I saw the color returning to her lips, I knew she was going to make it.

Within hours, she regained consciousness and I approached her to let her know what was going on. She heard what I was saying but could only nod to show that she understood. I explained to her what we had to do and why we did it. I told her that I had to wager that she did not want to die at this time. I asked her to forgive me if I was wrong.

Two days later, we were able to disconnect her from the respirator and remove the tube from her throat. I was very anxious to hear her first words. She cleared her throat and looked over to me and said “Thank you,” as I breathed a big sigh of relief.

I am telling you the story of this close call to impress upon you the importance of making your wishes known and doing it correctly. If you become seriously ill, your life and your quality of life can hang on a thread. The decisions you have made in advance and the decisions made on your behalf by your representative can significantly alter the outcome and the treatment you may or may not receive. To say that these decisions are not easy, would be an outrageous understatement. It took me many years of dealing with situation after complicated situation to feel comfortable with making the decisions for what I would want for myself and people for whom I am responsible.

Have you given any thought to what you would want if you became seriously ill?

If you were to come down with a terminal illness or you are incapacitated to the point that you are no longer able to communicate your wishes to others, how far would you want them to go to keep you alive?

Have you named someone who can make decisions on your behalf if you are no longer able to?

- Would you accept a feeding tube?
- Would you want to be kept alive on a respirator?
- Would you want CPR to be performed?
- Would you want to go through surgery?
- Would you take dialysis?
- Would you accept blood transfusions?
- Would you want to be hospitalized or do you want to die at home?
- Under which circumstances would you want or not want these treatments?

As a House Calls physician, these are the questions I ask my patients every day. I have dedicated my practice to

servicing home bound senior citizens, most of whom, are facing the end stages of their lives. At the time of this writing I have made over 10,000 visits to elderly and disabled patients in their homes. I also visit patients in the hospital and nursing homes. Because of the nature of my practice, I have the opportunity and the privilege of guiding patients and their families in making some of the toughest, most painful decisions of their lives.

Once I explain the terminology, most people know what they do and do not want for themselves in an end of life situation. As important as it is, too many people still put it off and avoid letting anyone know what their wishes are. Fear seems to be the biggest reason for the procrastination. Fear that making a decision would somehow “jinx” them and cause them to meet an untimely death. Fear that, they may fill out a living will incorrectly. Even fear of the perceived expense of having an advance directive made out, will prevent some people from taking action.

What people really should be fearing, are the consequences of suffering an incapacitating illness without having made their wishes known. It is sad and unfortunate when a person is simply kept alive, sometimes in pain and discomfort, because no one knows what she would have wanted. It always pains me deeply to look into someone’s eyes and wonder “is this really how you would have wanted the end of your life to be?” Without an advance directive, I can only guess. Most people I ask tell me they would not want to be kept alive and be a burden on their families. A few tell me that they would want to be kept alive by any means because “Where there is life, there is hope!”

The real tragedy of not having an advance directive is the impact it has on the families and caregivers. One of the cruelest things you can do to the people you love is to leave them with the responsibility of making health care decisions for you and not leave any directions to guide their decisions. Although, making these decisions for yourself may not be too difficult, making the same decision for someone else can be agonizing.

### **Mr. Smith**

Here is a hypothetical example of a typical new patient for me. Let’s call him Mr. Smith. The family asks me to consult on the case because the patient was just released to home after his fourth hospitalization for pneumonia. He has advanced Alzheimer’s disease and his doctor has informed the family that he is getting the pneumonias because he has “forgotten how to swallow.” The food that he eats is going down the wrong tube and into his lungs. The doctor gave them a choice: “Next time he gets a pneumonia, we can either keep him comfortable and let the pneumonia take him, or we can decrease the risk of getting pneumonias by putting in a feeding tube and not giving him anything by mouth.”

If the family shows me a living will and it says something like, “I value my independence and quality of life. If there is no reasonable chance of returning to a good quality of life, I would like all life sustaining measures withheld or withdrawn...” I tell the family “You are off the hook.” They do not have to make any decisions about the feeding tube. Alzheimers disease is a progressive and terminal condition. Mr. Smith’s advance directive clearly states that he would not want life sustaining measures, which would include a feeding tube. Neither the family nor the doctors have any right to override the decision that the patient himself has made. He absolutely has the right to be allowed to die a natural death. Of course, I would counsel the family and let them know that dying of pneumonia is actually a peaceful way to go and that they used to call pneumonia “the old man’s friend.” We can give him medications to make it more comfortable for him, but I would make it clear in

no uncertain terms that we have a legal and moral obligation to honor his wishes.

If Mr. Smith has no living will but one of the family members, Jane, says: “When mother died of cancer five years ago, daddy said, ‘when my time comes, I don’t want any of these things. No respirators, no feeding tubes, just let me go.’” I would tell the family that this is the same thing as making out a written living will. When you make a decision for somebody, you, as the patient’s representative are obligated to make the decision that *he* would have made to the best of your knowledge. In this case, Mr. Smith did state his wishes to Jane. As long as he had the mental capacity to make that decision at the time he said it, a verbal request must be honored.

Another family member, John, may argue: “Our minister says that we have to do everything we can to preserve life.” I would have to tell him, “If you agree with that and that is how you truly feel, then you should go make out a living will for yourself as soon as possible so that your wishes will be carried out for you. As far as your father goes, he told you what he wants. It’s *his* decision, not yours, not mine and not your minister’s.”

The only time that I may not carry out a person’s verbal directive is if another family member says something to the contrary. John might say: “When daddy spoke to me four years ago, he said that after talking with our minister, he decided that he changed his mind. He said that he would accept a feeding tube and wants whatever was necessary to keep him alive for as long as possible.” If this were truly the case, then I would be inclined to arrange for a feeding tube to be placed.

A verbal directive is often problematic. Although I am obligated to honor verbal directives, I have no way of knowing who is telling the truth. In this case, Jane may counter John by saying: “Daddy said no such thing. You haven’t even been around to see the agony that he was in knowing that he was losing his memory. I’ve been with him every day since he was diagnosed with Alzheimer’s disease and he dreaded the day when he would lose his independence.” Now I have a problem. Whom do I believe?

If Mr. Smith had named one of his children as the Healthcare Representative, that person would be the one that I listen to. If he named Jane as his Healthcare Representative, he should have done so because he felt that she was the person most likely to make the decision he would have wanted. In this case, I would have to listen to Jane. Hopefully he left a written and witnessed document naming her as his representative. This brings up an important point. When naming a Health Care Representative, you should name one person and then an alternate. List the order in which you would want the representatives to be appointed. Making a statement like, “I would want my wife and children to be my Healthcare Representatives” is no help at all. You want to name one person that you feel is most likely to make the decision that you would want. If this person is unable to or unwilling to take on the responsibility, then the alternate can do it.

By now, you should be getting an idea of how this works. Let me summarize it again because this is very important. When you are making healthcare decisions for someone who is incapacitated, your responsibility is to make the decision that you feel the patient would have wanted. You are NOT making the decision that YOU want. Understanding this will not only help you to make the right decision, it will relieve you of some of the feelings of guilt that you will have when making these very tough decisions.

When I meet a new patient, I always assess their capacity to make decisions. If I feel that the patient is able to

make his or her own decision, I always make it a point to discuss end of life issues with them. Many times, the patient will not have an advance directive and will be reluctant to talk about it. Often they may say that they are leaving the decision up to their children. At that point I will tell them right out that this is a very selfish decision. If you are able, you **MUST** make the decision yourself. It is absolutely unfair and cruel to put that burden on somebody else.

The vast majority of people, young and old, will tell me that if they are in a situation where they are progressively deteriorating and they have no meaningful mental capacity, they do not want to be resuscitated or kept alive in a vegetative or incapacitated state. However, when I ask family members of mentally incapacitated patients to make the same decision on behalf of the sick patient, they have a much harder time. Unless there is a verbal or written directive from the patient stating his wishes, the decision not to perform life sustaining measures is never easy, no matter how sick and in pain the patient may be.

## **Terminology**

Now that you have a feel for some of the issues that will come up in making a living will, lets' go over some of some terminology.

### **Living Will (Instruction Directive):**

A "Living Will" is not the same as a "Last Will and Testament". The Living Will is a document that pertains to healthcare issues. It is a document in which you decide in advance the kind of care you would want if for any reason you are unable to make health care decisions for yourself. Many people have an official Living Will drawn up by an attorney and have it witnessed and notarized. This is probably the best way to make sure your wishes get carried out and enforced. But it is not necessary to do it this way. Having **SOMETHING** is always better than nothing. You can handwrite your wishes on a piece of paper and sign it and it is still binding. It could be verbal, but the person you told your wishes to may have a difficult time carrying out your wishes. If it is not written down and somebody challenges it, your representative has no way to prove that these were indeed your wishes.

### **Advance Directive:**

An "Advance Directive" is the actual wishes of the person making out the living will. So a Living will documents the advance directives that the person wants to be carried out.

### **DNR:**

A third term that is often confused with the Living Will and Advanced directive is the Do Not Resuscitate order (DNR). The DNR can be a part of an advance directive, but confusing a DNR order with a Living Will could be a big mistake. A DNR order states that, if your heart stops or you are unable to breathe on your own, the doctors and healthcare professionals are not to attempt to bring you back. CPR, breathing tubes, electrical shocks to kick start your heart, and medications that help restart your heart and maintain blood pressure are not to be given if you have a DNR order as a part of your advance directive. There is also what we call a "partial DNR" in which certain parts of a resuscitative effort are accepted and others are not. For example, someone might request that chemical resuscitation with medications is acceptable but not shocks, or breathing tubes.

A DNR order should be reserved only for people who are suffering a terminal or progressive illness that could lead to great pain and discomfort in the end stages, or for patients who are currently suffering due to the illness and do not wish to continue living. In essence, a DNR order says “If I die or I am actively dying, my death would be a blessing because it would stop or preempt the suffering that I find unacceptable.”

A person could have an advance directive asking to be made DNR under specific circumstances.

### **Cardiopulmonary Resuscitation (CPR):**

This term is used to describe a set of procedures that are done to restart the heart and provide artificial respiration for someone whose heart and breathing have stopped. CPR generally refers to the action of pumping on the chest to manually squeeze the blood through the heart. A rescuer will start CPR if there is no pulse. CPR is usually performed on someone who is clinically dead. Broken ribs are not uncommon when CPR is performed, especially on elderly patients.

### **Defibrillation (Shocking):**

This term refers to the process of sending an electrical charge through the heart to jumpstart the electrical impulses that normally tell the heart to beat. Defibrillation is performed when the heart is not getting the proper electrical signals and is beating so erratically that no blood is pumping through the heart.

### **Intubation:**

This is a procedure where a short plastic hose (an Endotracheal tube: ET tube) is inserted in through the mouth and passed down the throat into the trachea. The end of the hose rests just above where the trachea divides and goes to the lungs. The other end of the tube is connected to a bag that the rescuer will squeeze to force air into the lungs. The tube will later be connected to a Respirator machine which will do the breathing for the patient.

### **Tracheostomy:**

After a patient has been intubated, the doctors will try to stabilize the patient to the point where they can breathe on their own. If the patient appears to have permanently lost the ability to breathe on his own or if it looks like it will take more than a couple weeks before the patient can be safely taken off the respirator, the doctors will want to do a tracheostomy. The ET tube can cause permanent damage to the trachea and vocal cords if it is left in too long. The tracheostomy is a surgical procedure where a hole is made in the neck just below the Adam’s apple. A little plastic or metal tube is placed through that hole and passed directly into the trachea. This tube can then be connected to the respirator machine.

A tracheostomy can be useful in situations where the breathing is compromised due to a malfunction of the breathing mechanism or an obstruction in the upper airway. A person who has surgery to remove a cancer of the vocal cords may require a tracheostomy and may be able to live a decent life with the “trach”. He may even be able to learn to talk. A tracheostomy may be useful for people who are so sick that they need to have a respirator machine to help them breathe for a prolonged period. If she needs more than two weeks on a respirator to get over a bad pneumonia, a tracheostomy will allow her to stay on the machine longer until she is recovered enough to breathe on her own. Some conditions such as Lou Gehrig’s Disease will cause a person to be unable to breathe on his own, but will leave the mind intact. In this case the patient himself may request a

tracheostomy so that he can be hooked up to a respirator. Many people lead a very productive life with a tracheostomy.

I strongly oppose performing a tracheostomy on a person who is unable to breathe because of irreversible lack of brain function. If a patient is so brain damaged, whether from dementia, stroke or trauma, that he is not able to breathe on his own, I try to urge the family to let him go. I have only had a handful of cases where the families insisted on a tracheostomy on a brain damaged patient. I cannot say that I felt any of these patients had a decent quality of life. My personal opinion is that a tracheostomy is cruel (unless the patient requests it or is expected to get better). In these situations, the only person that should be allowed to consent to a tracheostomy is the patient himself!

### **Feeding Tube:**

A feeding tube is used when a patient is unable to eat on her own. If a patient is unconscious, a feeding tube can keep her nourished with food and fluids. A feeding tube can also be used when a patient is conscious but unable to swallow safely. The food could go down the trachea and into the lungs instead of down the esophagus and into the stomach. In order to prevent pneumonia from aspiration, a feeding tube can be placed and the patient will not be allowed to eat by mouth.

A temporary feeding tube can be passed through the nose or throat into the stomach. This method is used when a patient is expected to recover from loss of consciousness or loss of ability to swallow. A patient may be lethargic due to a severe reversible illness, or she may have had a stroke and lost the ability to swallow. Sometimes, after a stroke, the ability to swallow will come back after a few days or weeks.

If it looks like the inability to swallow is a permanent condition, a more permanent feeding tube will be used. As you can imagine, having a tube go in through your nose or mouth can become very uncomfortable. The tube can also start eroding your nasal passage and throat. A permanent feeding tube can be placed through the skin of your abdomen and inserted directly into the stomach. This procedure is usually done in the operating room by an endoscopist and a surgeon. Under sedation, a tube with a camera on the end of it is passed from the nose or mouth into the stomach. While watching from inside the stomach, the surgeon pokes a hole through the skin of the belly into the stomach. The feeding tube is then passed into the stomach and anchored in with a rubber stopper or a balloon at the end of the tube. The other end of the tube is now sticking out of the abdomen and can be attached to a pump which delivers the feedings. The tube can also be left capped and formula can be poured down the tube at regular intervals.

A patient can be given nutrition temporarily through an IV directly into the blood stream, but this is not sustainable. In order to provide long term feeding to a person who is unable to swallow, the food must be delivered into the gut. The best way to do this is by the feeding tube.

Just like with the tracheostomy, my opinion is that a feeding tube should only be placed in people who are expected to have a decent quality of life after the tube is placed. Although it is done frequently, I do not agree with placing a feeding tube in people with permanent and progressive brain damage.

### **Dialysis**



This is a procedure that replaces the function of the kidneys. Kidneys clean the blood. If both of a person's kidneys fail, the person will die of uremia. Death can be avoided by cleaning the blood with a dialysis machine. This would be an ongoing procedure. Dialysis is typically performed three times a week. The patient would need to be hooked up to a hemodialysis machine and the blood is taken out of the body, cleaned through a machine and replaced. The patient usually has to travel to a dialysis center each time for this procedure to be done. This is not a painful procedure but is often uncomfortable because of the constant travel to and from the center. Also, the access site often fails and the patient may have to endure frequent surgical procedures to regain access by revising a graft or putting in catheters. A procedure called peritoneal dialysis can be done by the patient at home, but this method is prone to infections and is not really an option for debilitated persons.

Dialysis is intended for people who develop kidney failure but could otherwise survive. People who are otherwise healthy can come off of dialysis if they receive a kidney transplant. When kidney failure occurs as a part of the dying process in which all the organs start to fail in a domino effect, dialysis is considered futile.

### **Brain Death:**

Each State has its own legal definition of brain death, but generally brain death refers to a condition in which the patient is in a coma with no brainstem reflexes, there are no brain waves present, and the patient does not breathe on his own. His heart may continue to beat only while he is on life support. A brain dead person is considered to be dead, and has zero chance of ever regaining consciousness. His heart will stop beating when the life support is removed. The only reason to keep a brain dead person on life support is to harvest his organs. The doctors generally do not need the family's consent to take a brain dead person off of life support. Some States will require a brain dead person to be kept alive if the family requests it for religious reasons.

### **Coma:**

A coma is a state in which the person is unconscious and cannot be aroused, even by painful stimuli. The eyes will remain closed in a coma. The person must be in this state at least an hour to distinguish it from other conditions such as fainting or concussion. A coma can be reversible.

### **Persistent Vegetative State:**

This term refers to a person whose mental awareness is severely and permanently altered with no awareness of self or environment, no interaction with others and no meaningful response to stimuli. The person must be in this state for a period of at least 3 months before he can be determined to be in a persistent vegetative state (in the case of traumatic brain injuries, the diagnosis can be made after one year). A person in this state can move. He can move his arms and legs in meaningless ways but show no purposeful movement. He may open his eyes, blink, smile, grunt, yawn, scream and even shed a tear. These types of reflexes could be misleading and may give false hope to caregivers. Careful studies of patients in this condition have failed to show any evidence of psychological awareness or the capacity to engage in learned behavior. One way to determine awareness is to see if they have any "visual pursuit." Someone in a persistent vegetative state might briefly move his eyes towards a noise but will not track a moving object with his eyes or withdraw from a threatening gesture. He may or may not require a respirator to breathe. He will not be able to eat on his own and will always be on a feeding tube.

### **Locked-in Syndrome:**

This is a very rare condition but worth mentioning. A person can be in completely paralyzed due to rare neuromuscular conditions or due to drugs such as anesthesia. Someone in this state would have complete awareness of everything that was going on around her, but unable to communicate due to the complete paralysis. In contrast to the person in a persistent vegetative state, someone who is “locked-in” may be able to communicate by eye movements.

### **Mentally Incapacitated:**

This term refers to anyone who’s level of awareness is below their previous level. A stroke may cause a person to lose his ability to speak, he may even lose the ability to express his wishes in nonverbal ways, but he may still have the capacity to understand everything that is happening. Someone with Alzheimer’s disease may forget the names of all her family, but otherwise perform her own activities of daily living. These people will usually need some help making medical decisions.

### **Terminal Illness:**

If a patient has a condition which is incurable and will lead to her death, she can be considered “terminal.” The timing of when the death is expected to occur is debatable. Some physicians will consider a disease terminal if the patient is expected to die from it within 6 months. Others will not give a time frame. A person with Alzheimer’s disease can be considered terminal, but he may not die from the disease for many years. Diabetes is essentially incurable but it can be managed with medications. Although diabetes can decrease your life expectancy, it is not generally considered to be terminal. Even HIV is not considered terminal anymore because it can now be managed with aggressive medical treatment.

For the purpose of an advance directive, I will go over some of the conditions that I would consider terminal. As mentioned before, I consider advanced Alzheimer’s disease to be terminal. There are some medications that can temporarily slow down the deterioration, but the disease is progressive. Even with medications, the patient will continue to regress down a predictable path. I consider a patient with cancer to be terminal if it has spread to the point that there is no treatment available to cure it or push it into remission. It is terminal if she has other medical conditions that would make it impossible for her to receive potentially curative procedures such as chemotherapy or a bone marrow transplant. Very old age, emphysema, severe heart disease or even the patient’s decision not to accept the risks and side effects of treatment could push the cancer patient into the terminal category.

Parkinson’s disease and Multiple sclerosis can be considered terminal in the end stages, but people with these conditions often live a relatively long life after they are diagnosed. ALS or Lou Gehrig’s Disease is a less common disease but it is considered Terminal. Some people with this disease will die within a couple of years of diagnosis, but others will progress very slowly and can live a productive life. A stroke will destroy a part of the brain and some of the functions that are lost may never come back. A stroke victim will usually not get worse unless he has another stroke, so I do not consider him to be terminal unless the stroke is severe and compromises his breathing or complicates other medical illnesses.

### **Incurable and Irreversible Conditions that are not Terminal:**

This term is often used in a living will to describe some of the borderline conditions described above. Examples would be: Someone who has had severe brain damage from a stroke or accident, someone who has emphysema,

congestive heart failure or HIV infection.

Regardless of whether a condition is terminal or not, everyone has the right to make decisions about what is and is not acceptable to them. One person may decide that having a stroke and not being able to speak or walk is unacceptable. He may decide that under those circumstances, he would want to leave this world as soon as anything would take him. He may decide to put that in his living will and request that he be made DNR under those circumstances. Someone else might feel that he could still have a decent quality of life even with these disabilities and would request that a feeding tube be placed if necessary.

### **Hospice**

This is a program that is set up for patients who are terminal and expected to live less than three to six months. The goal of the Hospice program is to shift the emphasis from treating the condition to keeping the patient comfortable. A typical Hospice program will have nurses who are trained and experienced in dealing with the issues connected with a dying patient.

### **Competence**

Competence is a legal term. Only a judge can determine that a patient is incompetent. The term we use in the medical field is "Capacity." If two attending physicians agree that a patient has the capacity to make a certain decision, the person is usually allowed to make his own decision on that particular matter. A person with Alzheimer's disease may be so demented that he does not have the capacity to understand the risks and benefits of a surgical procedure. However, the same person can still have the capacity to decide if his life is still worth living.

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I hope the information that I have presented here will help you as you make the very difficult decisions for someone you care about. If you do not have an advance directive made out for yourself, I urge you to do it as soon as possible so that you can spare your family the burden of making these complex decisions for you. May God bless you and guide you as you make your choices.

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