

On February 15, 2008, for the **Education Channel of [Growth House Radio](http://www.growthhouse.org/radio_channel_education.html)**, **Les Morgan** interviewed **Stanley A. Terman, Ph.D., M.D.**, Medical & Executive Director of Caring Advocates, on “**The Option of Voluntary Refusal of Food & Fluid.**” The topics covered included: Why some terminally-ill people stop eating and drinking; psychiatric assessment for depression, anorexia nervosa, mental competence, and control needs; legality and ethics of this choice; the medical effects of dehydration and ketosis; how the family may respond to the patient's decision; assisted feeding of dementia patients; and advance care planning. Listen at http://www.growthhouse.org/radio_channel_education.html, or read the print version, which was edited for clarity, grammatical correctness, and completeness, and also includes an addendum of a real patient example. The print version is dated June 24, 2008.

Les Morgan: I'm Les Morgan of Growth House and today I'm interviewing Dr. Stanley Terman who is a psychiatrist and an MD. Dr. Terman, can you briefly give us some information about your experience in end-of-life care?

Dr. Terman: I've been a psychiatrist for about 30 years, and I have always emphasized relationship work. About 12 years ago I realized that the final opportunity for healing often occurs when time is limited by a terminal illness. So I became intensely interested in helping families with a terminally ill loved one so that all can experience peaceful transitions.

Les Morgan: Dr Terman, you've written a book entitled **The BEST WAY to Say Goodbye: A Legal Peaceful Choice at the End of Life**. One of the issues in the book is the Voluntary Refusal of Food & Fluid. Can you tell me more about that?

Dr. Terman: Voluntary Refusal of Food & Fluid is at one and the same time both *conventional* and *revolutionary*. Prior to the introduction of medical technology, people very often died by ceasing all intake of food and fluid. Now that we can insert many tubes into bodies, we can maintain people without consciousness for many years. Case in point: 15 years for Terri Schiavo. The question is, just because we *can...* *should* we? The *revolutionary* aspect of Voluntary Refusal of Food & Fluid and the book is to suggest that there are times when we may want to refuse food and fluid, not only by tubes, but also by manual assistance, even if we have the ability to swallow what someone puts into our mouths.

Les Morgan: Do you encourage patients to use Voluntary Refusal of Food & Fluid?

Dr. Terman: I never encourage patients to hasten their dying. Nor would I suggest any method that would certainly lead to an earlier death. But what I will do is to share with patients my professional knowledge about several options from which they can choose.

Les Morgan: Dr Terman, I've seen patients in hospice who stop eating or drinking, even though they are able to. What's going on?

Dr. Terman: Patients who are terminally ill with cancer often lose their appetite for food, and later on, also their desire to drink as well. They don't want to put anything into their bodies because it makes

them feel sicker. We have learned much from alert terminally ill cancer patients about what it feels like to fast. Other patients may decide that while they still enjoy eating and can swallow perfectly well, they have a rather dismal future to look forward to. For example, if they hung on to survive another few months, they would experience excruciating pain in their bones from metastatic cancer. Other patients may be only a few days away from dying and they decide that they would rather die from dehydration than from untreated pneumonia. Voluntary dehydration can be much more peaceful than dying from the toxic effects of coughing, fever and shortness of breath that often accompany pneumonia.

Les Morgan: So I'm trying to distinguish two situations. In one, you have what might be called a natural dying process in which the body turns off its desire to eat or drink. The other includes patients who still have the ability to eat and drink, but choose not to, because they're concerned about the course their disease will take and how difficult the last stages will be. In effect, they stop eating and drinking voluntarily. Then, they die. Isn't that a form of suicide?

Dr. Terman: No, I do not believe that it is suicide. As a psychiatrist, I'm totally against suicide, which I define as an act by someone who is medically well and has the potential of more years of a full life ahead of him or her, but for emotionally-based reasons that are irrational, wants to end his or her life now. In contrast, a terminally ill patient if given the choice would say, "If you could take away my disease and its suffering, I would love to live. Unfortunately, the reality is that I do have this disease, that it's irreversible, that it's progressive, and that it's going to kill me in an awful way. So I want a choice of how I die. I certainly do not want to prolong the process of my dying."

Terminally ill patients are not committing suicide. We will all die someday. For those who are facing the last chapter of life, that day will come sooner than for most of us. But when we get to the point that we have a definite terminal diagnosis and we know what the prognosis is, then -- just as we can decide what kind of treatment we want when we're well so we can feel better -- we can also decide what kind of treatment we want as we leave this life. Stopping eating or drinking is a way to die that does not prolong our dying process. When people stop eating and drinking, often the underlying disease is the ultimate cause of death; sometimes it is the change in electrolytes that occur. It is important to appreciate that this way of dying is peaceful: patients fall asleep several days before the end and they die while asleep.

Some people are surprised to learn that terminally ill patients do not always die sooner when they stop eating and drinking. Here's a common example: If they do continue to eat and drink, they may die sooner from aspiration pneumonia or heart failure. What's important to many terminally ill patients is not the exact time of when they will die, but that their dying will be peaceful. I've found that once people learn about this peaceful way, many will be comforted by knowing they have this choice.

Les Morgan: So this is a voluntary acceleration of one's death, correct?

Dr. Terman: Not always, such as when eating and drinking leads to an earlier death from aspiration pneumonia or heart failure. But it is, sometimes; for example, when it becomes very difficult for terminally ill cancer patients to eat, even though they might be able to force themselves. As people reach the last chapter of their lives, they give up things. One thing they may give up is the pleasure of

eating and drinking – because it is no longer a pleasure, as it may cause nausea or diarrhea. When they let go of eating and drinking, these people often feel a great relief. They can say, “OK, I'm done with that part of my life.”

Les Morgan: Dr. Terman, your specialty is psychiatry. How do you know that they're not just depressed when they want to stop eating and drinking?

Dr. Terman: Good question. I always advise physicians to rule out depression before they agree to provide Comfort Care if a person wants to stop eating and drinking. The patient's view of his/her situation should be realistic, not psychotically depressed, where their view of reality is not based in fact. For example, if a woman feels she is such a terrible person she must be punished by death, or a man feels he is such an enormous burden on people that the world would be better off without him, yet neither has a medical condition that would prevent living a normal lifespan. In contrast, someone with a terminal illness who can only look forward to much more pain and suffering, where most of the hours of every day are consumed with medical treatment, where there is no pleasure left in life... then their choice not to prolong the process of dying may seem reasonable. Of course they are not happy that they are suffering and they are not happy their lives will soon end. But they are interpreting reality correctly. They are not clinically depressed in the psychiatric sense.

Les Morgan: Would you call this “rational suicide”?

Dr. Terman: Others have used this term to describe a choice of the suffering terminally ill. “Rational suicide” means taking into consideration what your future existence has in store for you. If the burdens of living, or perhaps better said, of existing, far exceed the benefits, why prolong the process of dying? If all you have to look forward to is far more suffering and pain, with decreasing pleasure, it may seem rational to voluntarily refuse food and fluid.

Les Morgan: But many people would say, “This is just wrong! It's never appropriate to shorten your own life.”

Dr. Terman: Yes, there are people who would insist on using all that medical technology has to offer to extend biologic existence as long as possible. Sometimes these people come from orthodox or fundamentalist religious backgrounds. But remember: others who intensely share the same faith disagree point out that it is a sin to prolong life when God decides it is time to take the person to Heaven.

Les Morgan: If a patient came to you and they said "I know I'm going to die of 'X' within the next couple of months, I've decided to blow my brains out", how would you feel about that?

Dr. Terman: Terrible! I think blowing one's brains out is extremely painful, even though it is brief. It is violent, and it uses an instrument that could be used inappropriately to kill someone else that has a full life ahead of him or her. It is unsightly, doesn't make for an open casket, and worst of all, it is irreversible. When a patient maintains the resolve to refuse food and fluid over several days, it proves to everyone that she was really determined to Permit Natural Dying. But once you use a gun, or even take

a lethal dose of a barbiturate, your life is over. After you fall asleep, you can no longer say, "Hey, wait a second, I changed my mind." Only if you change your mind within a minute or two, can you ask people at the bedside to call an emergency medical team to try to save your life by pumping your stomach and using a mechanical ventilator to breathe for you. That rarely happens.

Les Morgan: Is it possible that people who are anorexic would choose this approach?

Dr. Terman: They do. And they have. This psychiatric diagnosis must also be ruled out whenever a person says, "I want to stop eating and drinking." Again, we need to distinguish between anorexia due to cancer, and anorexia due to the psychiatric illness called Anorexia Nervosa. The first leads to wasting from a total lack of appetite, sort of like a side effect from the cancer. The second, Anorexia Nervosa, is typically a young lady in her late teens or early 20's. When advanced, her condition can be a medical and psychiatric emergency for which it is appropriate to place her on tube feeding even she resists. In such cases to save lives, involuntary tube feeding is authorized by law. The state has an interest in preserving life and gives psychiatrists the power to override patients' verbally expressed wishes because aggressive psychiatric treatment often returns such patients to normal functioning so they can live a full and normal life span. In contrast, putting a feeding tube into a terminally ill cancer patient against his expressed wishes, including those he wrote down in his Living Will or Advance Directive, would be considered "battery" – an illegal intrusion into this patient's body.

Les Morgan: If you have ruled out depression and you've ruled out anorexia, is that it?

Dr. Terman: No, there's one more area to assess: to determine that the patient has decisional capacity; that is, the ability to use her mind to make prudent, sound medical decisions. She must understand what the options are available, appreciate the consequences of each alternative from which they may choose, use reasoning to arrive at a choice, and then they express that choice... and not just once, but consistently. Sometimes I'll interview someone for 2 hours, and note whether the choice she expressed at the beginning of the interview is the same choice at the end. Then I'll have them come back a few days later to see if this choice remains consistent. I also look for consistency in what she previously wrote or discussed with others. By the way, there is an easy way to remember these requirements for decision-making capacity: The initials of Understanding, Appreciation, Reasoning, and Expressing a choice has the mnemonic, U-ARE. I use this to teach the evaluation process to other clinicians. Here is a fine point: In the US, we use two words: capacity and competence. Psychiatrists offer the courts of law their opinion about "decision-making capacity." Judges use this as evidence to rule on whether or not the patient is "competent." Yet the need to go to court is rare.

Les Morgan: After you've completed your clinical interview and determined the patient has decision-making capacity, then they legally have the right to refuse food and fluid, don't they?

Dr. Terman: They absolutely have the right. The 14th Amendment of the Constitution includes privacy and the right to life, liberty, and pursuit of happiness. So we have the right to say what does and does not happen to our bodies including what people put into our mouths, our veins, and our stomachs. So if I say I don't want to eat, or drink, you can't force me to eat or drink if I am competent.

Les Morgan: So if you are competent, and you decide you don't want to eat and drink, that's an enforceable medical decision on your part?

Dr. Terman: Absolutely. The U.S. Supreme Court, in 1990, in the case of Nancy Cruzan, stated that every competent adult has the Constitutional right to refuse any medical treatment.

Les Morgan: Now, if you lose the ability to express that later on, maybe you have lost consciousness, this has to be documented clearly in your advance directive.

Dr. Terman: Yes it does. It must be clear and convincing. You must be precise about the specific condition or state for which you will want others to withhold food and fluid. But you do not lose your Constitutional right to refuse to consent to treatment, or to maintain the integrity of your body, just because you've lost consciousness or competence. You can transfer your right to make decisions to your designated proxy who would then be authorized to speak on your behalf. It's important for you to have advance care planning with your family, your proxy, and your physician so all can understand what options you prefer.

Les Morgan: If a medical provider helps with this in any way, is that assisted suicide?

Dr. Terman: The medical provider's assistance is limited to providing comfort care. The American Medical Association has a code of ethics which very clearly says that when a physician's duty is in conflict, between extending life and reducing suffering, and both cannot occur at the same time, then the choice is up to the patient.

Les Morgan: Do you know of any cases where a medical provider has been aware that a patient is refusing food and fluid, and they've been prosecuted for not intervening to force them to take in nutrition?

Dr. Terman: Absolutely not.

Les Morgan: That's a pretty short answer.

Dr. Terman: That is the answer.

Les Morgan: The concept of clear and convincing evidence is a legal concept you've mentioned. What it basically does is to introduce a higher standard of evidence for some medical decisions than others; for example, removal of a feeding tube is required to have clear and convincing evidence in New York State. What are your feelings about that?

Dr. Terman: In New York State, you can authorize your proxy to make all kinds of medical decisions for you and you can provide guidelines that make it obvious to all that you would not want food and fluid, but your Proxy or Agent cannot refuse artificial or oral administration of food and fluid on your behalf unless you – in those very words – grant them this specific authority.

Les Morgan: So if someday, you want the option to refuse food & fluid, is it a good idea to put it in writing?

Dr. Terman: More than a good idea: it is absolutely essential. If you can't write it down, you can make an audio or video recording.

Les Morgan: Is it difficult for the family to see their loved die during the fast?

Dr. Terman: Yes, first because their loved one is dying. Second because our culture is always to provide nurturance to those we love. So many ceremonies have to do with food and fluid, like wine for example.

Les Morgan: But there are negative side effects of eating and drinking when a person is dying because their body doesn't process food and fluid the same way it used to.

Dr. Terman: Yes, that is correct.

Les Morgan: For example, if you have congestive heart failure but you drink a lot of liquid, and there's no ability of the body to get rid of the liquid, you will feel like you're drowning because your lungs become congested.

Dr. Terman: True. For over 20 years Dr. Joanne Lynn has been educating healthcare professionals that when a terminally ill patient stops eating and drinking their comfort level increases in many ways, in many organ systems. When the lungs function better, you can get more oxygen to your brain and become more lucid, for example, which is surprising to some people. Sometimes, the first few days of their fast can be a precious time of sharing and exchanging memories and final goodbyes.

Les Morgan: Kathleen Singh says in her book, "The Grace in Dying", that dying is an inherently safe procedure and many of the problems arise because we interfere with it. In the case of eating and drinking, in some cases we might interfere with the body's natural effort to reduce its hydration level. Some people attempt to hydrate a dying person's body, but they do not understand some of the negative side effects. The result is forcing fluids on patients who might be more comfortable with less fluid.

Dr. Terman: Yes, I agree. There's much education needed, even among physicians. Studies have shown that the less experience a physician has in end-of-life care, the more likely he or she is to over-hydrate and thus add to the patient's burden. Thirst is a symptom but it's a symptom that can be effectively treated, and the family has to learn how to approach the patient. For instance, we don't ask the patient, "Would you like something to drink?" We don't even ask the patient, "Are you thirsty?" What do we ask? "Is your mouth dry?" That is a symptom. If the answer is "Yes," then we ask, "OK, what is your choice? Do you want to reduce the symptom of dry mouth with one or more thirst reducing aids? Or do you want to drink some fluid?" When patients are lucid and we've had prior discussions about this option, they can choose to remain consistent in their resolve to accept thirst reducing aids to alleviate the symptoms of dry mouth instead of drinking. Even a little fluid to wash down a pill several times a day can prolong the process of dying from the typical 1 to 2 weeks, to 3 to 4 weeks. This decision not to drink must be made over several days. Each day, the patient must maintain their resolve by saying, "No breakfast today; no lunch today; no dinner today; no food and no fluid, today." If they are lucid and communicative, I encourage family members to support what their loved one is doing, while reminding

them that they're not a burden and that it is really okay if they want to change their minds to have something to eat or drink. Then they can always start a fast again in a week or month or so.

Les Morgan: So the patient can back out of the decision.

Dr. Terman: Absolutely. Up to a certain point, the process is totally reversible. I know that myself, because I had two fasts. One was for 4 days of all food and fluid. The other was for 5 days, when I had water only for the first 2, and no food or fluid for the last 3. Although my kidneys got a little tired of the process, I'm still alive and well to talk about it today.

Les Morgan: Don't people insist upon feeding someone because they think that not feeding their dying relative is equivalent to killing him or her?

Dr. Terman: Yes, that can happen. Family members need help to understand what is the best way to help their loved one at the end of life. When I was with my stepmother as my stepfather was dying, she kept on asking, "What can I do? What can I do?" This was after we had asked him, "Do you want us to treat your dry mouth with thirst reducing aids or do you want something to drink?" and he replied, "Just the aids." A major part of my step mother's life was in the kitchen, making chicken soup and so many other wonderful and healthy items. Cooking and serving food was her way to nurture people. What she and many other family members need to learn is that when someone is dying and not eating or drinking, there is another way to show their love. They can learn how to increase comfort by using the thirst reducing aids, so that instead of pouring Sustical down the throat of a person who's going to choke on it, and then become bloated and more uncomfortable, they can learn how to use McKesson lemon-glycerin swabs around the inside of the cheeks and under and above the tongue; and Vaseline or Aquaphor on the lips. They can also use Biotene liquid drops or gel or any of a number of other aids. There is no limit to how often these aids can be used. Applying these aids can make caregivers feel important in another way, since they can no longer provide food and fluid. It is different way to nurture their loved one.

Les Morgan: What about ice chips?

Dr. Terman: Sometimes patients who get thirsty want ice chips, but I must caution people not to overdo it. Many small chips can add up. The more water taken in, the longer the process of dying will take. People who are inactive in bed can last for a very long time just drinking liquids. If you don't want to prolong the dying process, use as little fluid as possible. My book has suggestions to physicians as well. For example, many Comfort Care medications come in formulations that do not add much fluid.

Les Morgan: The idea that someone will voluntarily stop eating and drinking in order to speed up dying is going to upset a lot of people. Do you find that it's a controversial idea?

Dr. Terman: Yes, it is controversial, but mainly because it is misunderstood and mischaracterized. One of the misconceptions about refusing food and fluid is that the process is painful; for example during the Terri Schiavo controversy, one US congressmen claimed it was "cruel and barbaric starvation" – a gross mischaracterization. Research and clinical studies have shown that dehydration is one of the most

peaceful ways to die. Hunger is not a problem because the body naturally produces ketones that provide a slight euphoria, a state of well-being, which is a natural response to the lowered intake of calories.

Les Morgan: Is that what medical people call ketosis?

Dr. Terman: Yes. Certain metabolites break down to ketones, which activate our opioid system in the brain so we experience a slight euphoria including some pain relief. So instead of hunger, you feel even better. When I fasted, I experienced no hunger. Although patients with dementia cannot tell us what they are feeling, experienced clinicians who observe patients with advanced Alzheimer's have published several articles that indicate that patients who suffer from end-stage dementia actually increase their comfort during the two weeks before they die, after all food and fluid are withheld.

Les Morgan: In advanced dementia, patients usually require assisted feeding. Can you withhold that?

Dr. Terman: Sure. This is a very important area that will affect many people, and some aspects of it are controversial. Here's one way to think about it: Fluoroscopic tests can demonstrate that patients have an impaired ability to swallow so we conclude that they have lost the physical ability to swallow. This is a physical problem. Many studies show that tube feeding of patients will not provide an overall benefit to the patient in terms of quality or length of life. Although we might expect tube feeding to be safer, patients with dementia still get aspiration pneumonia, and other complications limit their life expectation. Furthermore, they often have to be restrained physically (tied down) to prevent them from pulling out the tubes, which in addition to being uncomfortable, increases the incidence of bed sores. Thus on the basis of this physical reason, we can reasonably Permit Natural Dying.

But what if the person doesn't know what to do with a bowl of puree, or a glass of liquid with a straw in it, when placed in front of her? Then they've lost the mental ability to eat and feed themselves. That's a mental problem. At the same time, they may also be in psychic horror. For hours a day they may screech, "Mommy! Daddy!" and live in angst. They may feel the kind nurse who comes over to the bed with a warm sponge to bathe them and clean them is going to assault them. What anguish these patients live in, because they don't understand. Why should we open their mouths and put food at the very back of their tongues so that they swallow by reflex? Why should we go to such efforts to prolong their process of dying when they are suffering mentally? Why can't we just Permit Natural Dying? We know that tube feeding has no proven benefit for quality or quantity of life for patients in advanced dementia. I believe people have just as much a right to refuse assisted oral feeding for mental reasons as for physical reasons. And they have the right to refuse orally assisted as well as medically administered food and fluid.

Les Morgan: Dementia is very common in the elderly, isn't it?

Dr. Terman: Yes, and it will become increasingly so. Four times as many people will suffer from dementia in 2050 as are currently suffering from it in 2008. The increase will go from about 5 to 20 million. And 43% of those will need total care in an institution.

Les Morgan: That's going to be rather expensive, isn't it?

DR. TERMAN: Enormous. The figures available today are probably underestimates, but the prediction is that it will cost a trillion dollars a year to care for Alzheimer's and related dementias by the year 2050. To put this into perspective, in the first 5 years of the Iraq war, the US reportedly spent about half a trillion. Can you imagine what it's going to do to our economy to spend 1 trillion dollars every year on Alzheimer's dementia and related diseases?

Les Morgan: Some people would say that not providing nutrition or hydration to someone who can't get it on their own is a form of euthanasia. Do you agree?

Dr. Terman: No I don't agree. But you're right: some would call the process "euthanasia." In March 2004, Pope John Paul II said that, for people in the permanent vegetative state, not to continue tube feeding is "euthanasia by omission." Pope Benedict XVI went even further. He added that patients must be fed by tubes even if they will never return to conscious life. Yet Pope John Paul II refused a feeding tube for himself, before he died. So did Mrs. Billy Graham. Not all spiritual and religious leaders agree with this point of view. Kevin O'Rourke is a scholar, a bioethicist, and a Dominican priest. He teaches that when someone no longer can have personal relationships and cannot express themselves, when they have lost the ability to understand how to eat and drink, then it's time to Permit Natural Dying. So does John Harvey, another Catholic theologian, who is also a physician and bioethicist.

Les Morgan: So opinions vary among bioethicists on this?

Dr. Terman: Yes, they do. If we return to the teachings of Pope Pius XII, he said the choice about refusing medical treatment to prolong life should be made by the individual, not by the religious leader. He also said the decision can take into account not only the physical and psychological burdens of the patient, but also the burden to the family and to society.

Les Morgan: Some medical people feel that insertion of a tube for feeding is medically futile treatment. What do you think about using this terminology?

Dr. Terman: The word "futile" means using a procedure or intervention that has almost no chance of restoring the patient to a level of functioning where she or he can have a quality of life that would permit living independently of constant, continued medical treatment.

Les Morgan: If a treatment is medically futile, are healthcare providers under a duty to provide it?

Dr. Terman: No, they are not under a duty to provide it. In California's Probate Code, there are two exceptions to providing treatment that patients ask for. One is if the physician believes that the treatment would be ineffective or far more of a burden than a benefit or of no benefit at all, which you referred to as medically futile. The other reason to object to treatment is when health care providers' conscience has a moral or religious objection.

Les Morgan: Laws vary by state, don't they?

Dr. Terman: Indeed they do, but most states have similar laws.

Les Morgan: What's the situation in Texas?

Dr. Terman: Texas has a uniquely effective law about futile treatment. If their institution's ethics committee agrees, physicians are not obligated to provide treatment they believe is futile. The Texas law requires the family -- not the physician -- to find another physician or institution willing to provide continued treatment. If the family is not successful after 10 days (which courts can and often do extend, but not indefinitely), then the treating physician can withdraw treatment to allow the patient to die. In contrast, other laws in other states place the responsibility on the physician to make a "reasonable attempt" to find another physician or institution willing to provide the care the family members insist they want on behalf of the patient. Meanwhile, the treating physician is obligated to continue treatment. With no set time limit for a "reasonable attempt," and with no other physician or institution willing to continue futile treatment, the process of dying can be prolonged indefinitely.

Sometimes one member of a family threatens to sue the physician unless treatment continues. Yet other members of the family and the physician agree the treatment is futile. To avoid such conflicts, I suggest taking three steps:

1) Appoint a Proxy you trust; 2) Create a clear and convincing Advance Directive that lists criteria that your Proxy and Physician can use as a guide; and 3) List any relative whom you want to disqualify as having any authority to speak for you. (Note: Since this interview was conducted, Dr. Terman created a new combination document called, "Physician's Orders to Permit Natural Dying." This Physician-Signed Advance Directive incorporates all of these recommendations.)

Les Morgan: Another psychiatric issue may be that people vary in the amount of control they like to exert on their environment. Some people, when they're dying, just accept it as God's will and say, "Well, I'm along for the ride but I'm not able to control it". Others are very concerned about the loss of control. How does this issue affect what you're proposing?

Dr. Terman: The issue of control is important to those who campaign to legalize physician-aided dying or as some people refer to it, Physician-Assisted Suicide. For example, a person might want to have a "send-off" party on a certain day, so they want to control which day they will die. That is not possible with Voluntary Refusal of Food & Fluid. You probably can estimate what week you will die, but not what day. If a person really has a great need to be in control, he or she may opt for physician-aided dying, which is only legal in the state of Oregon, the Netherlands, Switzerland, and a few other places.

If I were practicing in the state of Oregon, however, and someone asked me to provide a lethal dose of medication for physician-aided dying, and I thought they might have a control issue, I would ask a series of questions first. For example, "Why is timing so important to you? Is this a special day in your life? What's really going on here? Can we talk about your need to be in control? Are you afraid of dying?" In other words, I consider a request for a quicker way to die as cause to probe the patient's fears and help the patient come to peace with his or her mortality.

Les Morgan: You've said that knowing that you can choose to not eat and drink might actually cause people to live longer. How is that?

Dr. Terman: Yes. Life's greatest irony is that the freedom to control when we die – *can*, and often does – lead to our choosing to *live longer*. If society, if clinical medicine, if the way our laws work could really assure people that when they get to a certain point in their lives that they define ahead of time, that their existence – or better said, their dying – will not be unnecessarily prolonged, then they can choose to live right up to that point, and without anxiety. Otherwise, they may end their lives prematurely – when they *can*, instead of when they *want to*. I consider that a tragedy. Jack Kevorkian's first patient was 54-year-old Janet Atkins. She had early Alzheimer's disease so she could no longer teach history, play piano, or keep score in a tennis game. But she could still play tennis. She played a full set with her son, enjoyed it, and even won. But then she died... in Kevorkian's rusty old van. Later, her husband said that if she had known that there had been a way to live those extra two or three years with some degree of pleasure – if she could be sure that she would not have gone on longer than that, she would have taken that option. That was back in 1990. Now we know that she can appoint a proxy and give specific instructions such as, "These are my criteria: When I can no longer recognize those I love, when I can't remember my values and life, and what I stood for, then I want you to withhold food and fluid from me, and others..." Then she could have lived up to that point. That would have extended her life when there was still quality left. I feel that is very important. It's what I strive for: to extend the quality of life. (Note: the *Behavioral Criteria for End-Stage Dementia* are included in the survey, "**Is it Moral to Permit Natural Dying for Patients in End-Stage Dementia?**") It is possible to select certain pages with one's answers to print out and attach them to one's Advance Directive.)

Les Morgan: Is withholding food and fluid similar to mercy killing?

Dr. Terman: No, I feel that it's the exact opposite. So much money has been spent on political campaigns to legalize physician assisted dying, but it has failed many times in many states. I wish just 1/10th of the money spent could go instead to educating people on Voluntary Refusal of Food & Fluid and Withholding of Food and Fluid by Proxy, because sometimes, out of love, people commit mercy killings and the result can be quite tragic. Here is a sad example: Albert Pollock gave his wife of 60 years total devotion and love. She was suffering from advanced dementia from Parkinson's disease. After she refused pills and pushed away any effort to make her comfortable, he got what he considered as clear a message as he could. Because he didn't know about Voluntary Refusal of Food & Fluid and because his wife did not create an effective proxy directive, Albert thought his options were limited to help his wife when she no longer wanted to prolong her dying. He strangled her with a towel, called 911, and took a plea bargain to second degree manslaughter. So this 84-year-old loving man will spend the next 12 years in prison if he survives that long. This is not an isolated case, and my heart goes out to these people. If they had only known that all she had to do was to refuse food and fluid, all Albert had to do was to keep her mouth moist, and then he would not have had to go to jail. And even though what he did was out of kindness, he might still feel guilty because, after all, society is punishing him. We need to spread the knowledge to prevent such terrible tragedies.

Les Morgan: It seems these issues you're working on are involved with the right-to-die issues in general. Do you see it that way?

Dr. Terman: Not exactly. I see my work more as the right to choose the way we die so that our dying can be as peaceful as possible. Sometimes we can make decisions that will either prolong or hasten the process of dying but the primary focus is on reducing pain and suffering. I like to think of my work as promoting the opportunity to Permit Natural Dying as a way to avoid unnecessarily prolonging dying.

Les Morgan: Dr Terman, thank you for being with me today on Growth House Radio.

Dr. Terman: Thanks for asking me here, and helping to get these important messages out. The difference between end-of-life suffering, going to jail, and a peaceful dying for both the patient and the family, is worth working for. Thanks for giving me the opportunity to express these views.

Les Morgan: This is Les Morgan. Visit www.growthhouse.org to hear this interview.

Addendum: The following is a real case, with specific personal details changed to protect the family's identity. The choices here illustrate two goals of Caring Advocates (www.CaringAdvocates.org): A) To maximize quality and quantity of life; and, B) To achieve Peaceful Transitions.

A competent 89-year-old man, who is not terminally ill, wishes to refuse all food and fluid to hasten dying. He has a medical history of TIAs (transient ischemic attacks), some falling, some weakness, and moderate symptoms of "swimming in his head." Enjoyment of life is decreased due to his physical limitations. He needs 5 hours a day of semi-skilled assistance with ADLs (activities of daily living).

Family history is significant from the patient's point of view. His father and grandmother both endured unwanted prolonged dying after their respective physicians each promised them that this would NOT happen.

The man fulfills the criteria of decision-making capacity: He understands his treatment options and he appreciates their consequences. The two options are: Voluntary Refusal of Food & Fluid NOW, or, Refusal of Food and Fluid by Proxy LATER, when another medical crisis occurs. (I presented three examples of crises where his Proxy would then refuse food and fluid on his behalf: a major stroke, a broken hip requiring sedating pain medications, or a period of time without air leading to a Minimally Conscious State.)

When asked to explain his reasoning for NOW, he cited an example that he found meaningful: "A tax adviser encouraged me to give my home to my two sons, but then the government changed the law. You say, 'Wait until I have a terminal illness or sudden devastating physical incapacity,' but how do I know for sure the government won't change the law again?" (At that point, I had already advised him that if he had an emergency and happened to be transported to a faith-based hospital, it is possible that the hospital's bylaws might not permit his Proxy/Agent to fulfill his long-standing end-of-life wish to withhold all food and fluid.) While he lives close to a university hospital, his stated philosophy is, "All we know for sure is the present." He thus not only expresses his choice consistently, his determination is steadfast. Furthermore, he has discussed the option of Voluntary Refusal of Food & Fluid for several

months with family, friends, and physicians. He also feels this way of dying is consistent with having "found himself" and being in (relative) peace – in the Buddhist tradition.

He still has the ability to enjoy his family, reading, and several other activities so he does not seem to suffer from a clinical depression, yet he says he sees little point in continuing to live since at 89 he has had a full enough life and does not want to take the risk that befell his father and grandmother by continuing to live. His son stated he was willing to help his father with Comfort Care during his fast at home since initially, he did not meet the criteria to be admitted to hospice.

I tried to convince him that I could virtually guarantee that he would not end up like his father and grandmother with a new end-of-life wishes document that combined a Proxy Directive, Ulysses' contract, and Physician's Orders, but the old man would not accept this offer. Ultimately, I felt there was nothing further I could do but accept the man's resolute determination, while I informed him and his sons repeatedly that he could change his mind within the first few days of the fast. So I, and his sons, supported him in his final wish. Although the old man was comfortable at home with his son's care, I encouraged the son to keep on trying to find a physician who would certify his father as terminally ill so a hospice would admit him. After 3 days of refusing food and fluid, during which time the son asked several doctors and hospices to admit him, a hospice finally did accept the old man with the diagnosis of "Debility, Not Otherwise Specified." He died peacefully 5 days later.