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**Lifecare Directives, LLC**  
5348 Vegas Drive, #11  
Las Vegas, NV 89108  
[www.lifecaredirectives.com](http://www.lifecaredirectives.com)  
Toll Free: (877) 559-0527

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an Advance Directive?*



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is Right for You*



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# *Should I Complete an Advance Directive?*

*Making a Choice That is Right for You*

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## **Introduction:**

It has not taken most of us long to learn that in real life any choices we make usually have consequences, and that in making the most meaningful choices we are usually foregoing other potential options. Because of this, many of us are not inclined to make hasty decisions nor to proceed too casually or based upon too many assumptions. Just because an idea is popular or even recommended by “experts” does not always make it right for us.

As our time and energies are not boundless, most of us also invest our efforts in information gathering and decision-making in some reasonable proportion to the potential risks and benefits related to the decision to be made. Casual decisions with relatively obvious benefits are typically made much more quickly than those with a high potential for serious consequences or uncertain benefits. Thus, while we may face some measure of emotional tension, for example, when trying to select from a restaurant menu (and perhaps even more when it comes to our selection of the desert!), these transient decisions are usually much less stressful than, say, the decision to purchase a car or a home or whether or not to accept a possible job offer or questionable promotion.

Among the more serious decisions to be made in life are those related to our health care and the care of those we love. When these decisions also involve the use of “life-sustaining” medical treatments they rank among the most important choices that we may face.

Sometimes serious decisions are better put off until we are faced with an immediate need. After all, only then can we truly know all of the variables involved and all of the options available. At other times, however, “not to decide *is* to decide.” And so it is with the issue of advance directives – to make no advance choices for yourself and to share no personal preferences with others is definitely to defer even *life*-sustaining treatment decisions to the future uncertain judgment of others.

To fully understand this statement, some background information is in order.

## **What is an “Advance Directive”?**

The term “advance directive” refers to “*any* instructions you may make regarding your future health care, whether written or oral” (*see American Bar Association, Patient Self-Determination Act State Law Guide, 1991, pg. 1; italics added*). More formally the term refers to legally sanctioned documents that are used to leave personal “directives” (instructions) about your “advance” (future) health care wishes. Some of the more common advance directives include:

- The “Living Will”
- The Health Care Power of Attorney
- Medical Powers of Attorney
- Proxy Directives
- Representative Directives
- Treatment Specific Directives (such as those used to refuse blood transfusions or unwanted CPR, etc), and
- Organ Donor cards.

Here we will discuss only the two most common advance directives, namely: the living will, and surrogate appointment directives such as the medical power of attorney (also known in some states as a “health care power of attorney” or a “proxy” or “representative” appointment directive).

### **The Living Will**

The “Living Will” is the advance directive that is most widely recognized. It was created by an attorney, Luis Kutner, in about 1967 and first publicly proposed in a law journal in 1969 (*see: Kutner, L. The living will, a proposal. Indiana Law Journal. 1969;44(1):539-554*). It was designed to be a legal document in which you could record your personal wishes and instructions – much like a traditional estate will, but for use while you are still living (hence the name ‘living’ will) and limited specifically to issues of health care and medical treatments.

The motivation behind the creation of the living will was the rapid advancement of medical technology. Scientific progress was making it ever more likely that when and where one died and how much suffering one might endure were increasingly matters of personal choice. Historically, injuries and diseases took life very quickly and often prematurely. However, by the mid-1960's a great many people were having their lives medically prolonged for many years and often into poor health or even graphic states of debilitation.

The goal of the living will, therefore, was to let you write out those situations in which you would *not* want to have your life artificially prolonged by medical means. It was to be used only when you could not otherwise make your wishes personally and specifically known – i.e., when you had completely lost the mental capacity to make decisions or when you were entirely unable to communicate your desires to others.

The living will, therefore, was meant to be a safeguard against being unwillingly kept alive in situations of extreme suffering or profound debilitation when accompanied by a total loss of personal decision-making and/or communication ability. A major focus was on avoiding highly burdensome and painful treatments for those known to be “terminally ill” or in situations of permanent unconsciousness. The idea of a living will quickly became so popular that the public successfully pressed for and obtained specific legislative endorsement in virtually every state in the union and the territories. Supported by these formal state and territorial “statutes,” the living will became a legal document.

It was not long, however, before certain problems with the living will were identified. First, it was often too narrow in scope. Sometimes people had concerns well beyond just terminal illness and permanent coma, but could find no way to include their concerns in the

standard documents provided. Second, most living wills focused solely on *refusing* treatments, even though some people wanted to write out situations in which they wanted treatments to be accepted or continued as well.

Third, as living wills were focused mainly on medical “treatments and procedures,” it soon became apparent that there was no way to match every available treatment to every possible health problem in advance, much less accompanied by any narrative of wishes in all those situations. Such a document would be inordinately long and cumbersome. Further, because new treatments are constantly being invented the task could never be really be completed.

Fourth, it was also noted that any current effort to reject one or more treatments could easily become compromised later by situational conditions and circumstances. For example, a simple statement such as “I don’t want to be put on a breathing machine” could become a significant problem. Being attached to a breathing machine is a routine part of using general anesthesia in an operating room. You simply cannot breathe reliably when under general anesthesia, and if your airway is not protected by a breathing tube you could easily suffocate in accumulating fluids or from any sudden reflux of stomach contents.

Soon doctors found themselves frustrated by what appeared to be otherwise simple statements. They labored to determine, for example, those situations where someone might *still* have wanted to a breathing machine to be used – such as during a simple surgery to remove an appendix – in spite of what they had written down.

At other times the information provided was so vague and unclear as to provide no meaningful direction at all. A classic example are the common directives to “weigh the burdens versus the benefits” of any proposed treatment and to avoid any “undue suffering,” and not to use “extraordinary means” in hopeless situations. However, *exactly* when does a treatment become “burden” and *how* successful must it be to produce a “benefit”? *Precisely* what is “undue” versus “acceptable” when suffering is involved? *Specifically* which medical treatments are “ordinary” and which ones are “extraordinary”? At what *certain* percentage point do the odds of failure define “hopeless”? In this way many of the treatment choices and directives recorded in living wills were often found to be useless.

It was problems such as this that led to the “second generation” of advance directives, which included medical powers of attorney, health care powers of attorney, and health care proxy, surrogate, and representative appointments.

### **The Medical Power of Attorney/Proxy/Surrogate Appointments**

Regardless of the specific title, medical powers of attorney and other appointment directives had a very simple goal: to allow you to name someone you trust to make health care choices for you at any time that you are unable to make these choices for yourself. The advantages were immediately obvious. The doctor knows who should make any decisions, and the person making the choices can collaborate with the doctor in ‘real time’ and with the benefit of knowing the exact situation, all the treatment options, and the expected and specific burdens, benefits and outcomes of each.

This was a great advantage and the idea was very well received by the public. Again, it was not long before the public pressed for and promptly received legislative support for these documents. Thus, they were soon also legally supported in virtually every state of the union and



the territories.

As before, however, problems were soon discovered. First, most people who were appointed had absolutely no idea with their loved one would want done (indeed, a great many of them had no idea they'd even been appointed until they were called upon to make decisions). Second, making biased choices based upon the personal preferences of the appointed person was unacceptable. The recipient of the treatment was the one who had to live with (and through) the burdens that might be imposed, not the decision-maker. Third, making specific treatment decisions often left appointed decision-makers feeling like they were being pressed into 'practicing medicine,' which only physicians are properly trained to do. The usual response, therefore, was "what ever you say, doctor," rather than any deliberation over what an individual might actually want. It was soon clear that what appointed decision-makers really needed was a workable living will to guide them. Yet, that idea already appeared to be an impossible goal.

### **The Outcomes Content Solution**

Finding a workable answer required some historical review and rethinking. It was decades ago that one of the earliest living will reviewers made a crucial observation. She noted:

"[The living will] is not meant to impose more certainty and personal choice on dying than can be had. It is merely an effort to mitigate the worst effects of uncertainty [which]...may force health professionals – in the absence of patient instructions – to do unto others what they would not want anyone to do unto themselves" (see: Bok, S. *Personal Directions for Care at the End of Life*. *New England Journal of Medicine*. 1976;295(7) (12 Aug):367-69).

Recognizing this core goal led to the reevaluation of other past insights. For example, more than a decade ago a physician research team found that "patients desired information focusing more on expected *outcomes* than on medical processes," and, again, that the focus must be "on the *outcomes* of end-of-life care, in contrast to the *processes* of such care" because, "clearly, issues of death and disability outweighed concerns about endotracheal tubes and cardiopulmonary resuscitation" (see: Pfeifer, MP; et al. *The discussion of end-of-life medical care by primary care patients and physicians*. *Journal of General Internal Medicine*. 1994;Feb:82-88; italics added).

Still later another physician-led research team reached the same conclusion, noting that patients "were concerned primarily with the *outcomes* of serious illness rather than the medical interventions that might be used, and [they] defined treatments as desirable [only] to the extent they could return the patient to his or her valued life activities." They noted that, "advance directives and physician-patient discussions that focus on acceptable health states and valued life activities may be better suited to patients' end-of-life care goals than those that focus on specific medical interventions" (see: Rosenfeld KE, et al. *End-of-life decision making: a qualitative study of elderly individuals*. *Journal of General Internal Medicine*. 2000;15:620-25; italics added).

At about that same time yet another physician researcher further confirmed these findings, noting that "Patients retrospectively report wanting information about the disease (*prognosis*, further tests, treatment options), ...and the *impact* of the disease on themselves, their families, and their careers" and other health *outcomes* information, instead of the technical information they usually receive (see: Quill, TE. *Initiating end-of-life discussions with seriously ill patients*. *Journal of the*

*American Medical Association. 2000;284(19):2502-07).*

From these findings a “third-generation” of advance directives was proposed: the “outcomes oriented advance directive.” It was to focus on thresholds of mental and physical *function* and remaining *capacity*, rather than on specific treatments or on vague euphemisms that could not otherwise be realistically applied. Put another way, who cares *what* treatments or procedures are used, so long as an acceptable outcome can be achieved. Conversely, *any* medical treatment that cannot produce an acceptable outcome should be rejected (except those used for pain relief or other comfort) regardless of how cleverly it might manipulate immediate medical circumstances.

In this way a workable living will could be constructed that avoided the “worst effects” of unwanted medical intervention as defined by the person completing the document. Focused on health outcome situations, it also easily avoid the ‘practicing medicine’ problem by leaving medical treatment choices entirely up to involved physicians where such decisions properly belong. What was needed next, however, was a thorough review of those outcome conditions and situations that were of the greatest concern to the public.

### **Obtaining an Outcomes-Focused Advance Directive**

Thankfully, the requisite research has since been done and a comprehensive outcomes-focused advance directive is now available to the public. Known as the *Lifecare Advance Health Care Directive*, it is the result of more than 10 years of rigorous research. Its development involved the review of more than 6,000 articles from medical journals, legal publications, and writers in the popular press, along with the comparative review of more than 100 independently designed advance directives (i.e., not just multiple versions of a single generic document with subsequent minor adjustments to meet varying state criteria). This was followed by extensive reviews and input from scores of physicians, nurses, elder law attorneys, bioethics specialists, and many other scientific and secondary researchers. Finally, more than 1,000 lay persons participated in university-overseen research and testing. Through this process, the *Lifecare* directive was refined to include all the major concerns of the public. Not surprisingly, it was also found to be functionally superior to all other advance directive documents tested.

### **Should You Now Complete an Advance Directive?**

With the information provided, you now know that many of the prior limitations of living wills have been reduced or eliminated. Using an outcomes-oriented directive you are now able to not only properly record your wishes, but you can also more easily and more fully inform any person you may choose to represent you in making future treatment decisions in your behalf.

However, in spite of these advances and refinements, should you still complete an advance directive document? To better answer this question, let us more fully examine your current options and the potential outcomes of each.

#### **Option 1. Do Nothing.**

One option is to leave things alone and defer any advance decisions until some future time. In this way you don’t tie your self down to any prior conclusions, and your loved ones are free to choose for you as they later see fit. To more fully evaluate this option, let us look at some

actual case examples of people who chose this approach.

Case Example A. Maria was in her late 50's when she began to develop memory loss. At the time she was employed in a canned soup production factory as a line worker. As her memory began to fail, she and her husband often grumbled about the unfairness of her employer when she was repeatedly reassigned to progressively simpler (and lower-paid) work over the coming year, but they did not seek any medical help. Only after she finally lost her job did they see a physician who provided them with a diagnosis of early-onset Alzheimer's disease.

Over the ensuing years, Maria continued to slowly deteriorate. Her husband was a dedicated caregiver, and continued to care for her in the home long after she lost control of both her bowel and bladder and well after she required spoon-feeding entirely by hand. Even so, when she eventually became totally bed-bound, incoherent and grossly confused, he could no longer keep up. Maria was subsequently placed in a nursing home for around-the-clock care.

As her condition declined further she became entirely immobile until she could not even move herself to shift her position in bed. During this time she experienced several life-threatening episodes of pneumonia and other systemic infections, any one of which could have taken her life without medical intervention. However, no one knew of her wishes. Her husband could not conceive of any option except pressing forward, so every available medical treatment was provided.

In the natural progression of things, Maria's muscles gradually withered entirely away and became ligament-like fibers. Over time, and in a continued natural course, these ligamentous fibers shortened and tightened and she gradually assumed a fetal position, with her arms permanently flexed upon themselves, her knees drawn to her chest, and her hands balled-up in perpetual fists. The muscles of her jaw also withered and shortened, slowly driving her teeth forward and outward, or upward and into the roof of her mouth. She was, of course, entirely tube-fed.

Nursing care became extremely difficult. Turning her caused significant pain, and bathing was almost impossible. Moving her for cleaning and bed changes was onerous and challenging. Staff at times lost their grip and slipped and dropped her. Skin erosions, pressure sores, and other symptoms became increasingly common. Life-threatening infections, pneumonias, and other problems continued to emerge but they were always overcome with the regular use of increasingly powerful antibiotics.

Finally, surgical intervention became necessary. Her hands, permanently balled-up as they were, could not be kept clean of old skin debris, sweat and body oils. Further, her fingernails had begun growing through the palms of her hands, leaving her at perpetual risk of infection. Ultimately she was brought to the hospital for the removal of her mid-finger bones, which would then allow her hands to be opened and cleaned and her fingernails trimmed. At the time of

surgery she was already in considerable pain, having recently suffered broken bones due to advanced osteoporosis and a recent slip and drop by nursing home staff. Indeed, her husband was in process of suing the nursing home for negligence at this most recent injury.

Maria's surgery was successful. However, during her recovery she developed yet another virulent infection which soon progressed to pneumonia and spread throughout her system. It had never been possible to wean her entirely away from the breathing machine used during her surgery. She was drawn into such a tight fetal position that her breathing was perpetually impaired and she was unable to cough to expel the fluids that accumulated from her pneumonia. Therefore, hospital staff routinely (and very painfully) pushed suction tubes down into her lungs to draw out these fluids. Maria endured the constant suctioning, and winced and moaned at every effort to turn her. Yet, any failure to turn her frequently left her at great risk of pressure sores, which could quickly expand into large open and draining wounds. Thus she was turned promptly and often, in spite of the pain of her broken bones and the natural tenderness of her advanced arthritis.

In spite of it all the husband could not bring himself to consider turning off the breathing machine nor to forego the antibiotics for her pneumonia and other system-wide infections – even though liberal comfort care medications could have entirely relieved her pain and any air-hunger she might have experienced from the advancing pneumonia. Therefore her medical treatments and invasive interventions continued painfully for several weeks.

Finally, Maria succumbed to an overwhelming infection while still on the breathing machine, and she died having suffered long and profoundly from her surgical wounds, her arthritis, the broken bones, her raging fevers, and the unending suctioning of her lungs, constant turning, IV line changes, etc.

*Conclusion:* Maria had apparently never told her family anything about her personal wishes, and she had not put anything in writing. High quality medical care was therefore continuously provided and her life was repeatedly extended artificially, by feeding tubes, antibiotics, and mechanical ventilation. Great suffering resulted. While her husband appeared to be very involved and attentive, there was some speculation that perhaps he pressed for further treatment only because of the lawsuit (as a 'pain and suffering' suit he would not collect any money unless she survived to its conclusion). However, there was no clear evidence that this was his primary motivation.

Considering all the information here provided, it is now important for you ask yourself if, is the demise experience that you want? Would you want your life to be artificially extended to such a great extent? Further, should your loved ones be left to bear all these decision-making burdens without any input from you? Would you be comfortable with speculation that your loved ones might be acting only out of a desire for monetary gain, rather than out of a desire to honor your wishes? These are some of the possible outcomes of the "do nothing" approach.

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**Case Example B:** Joseph was in his early 70's when he developed lung cancer. By the time it was discovered, the cancer had become widespread and was inoperable. For many months he remained generally comfortable with only moderate medical intervention and medications. There came a time, however, when he experienced a sudden and acute deterioration. His breathing became labored and the area between his lungs and his chest wall rapidly began to fill up with fluids. Joseph was soon stuporous, confused, and unable to communicate. At about this time he became unresponsive and his wife called “911” for immediate assistance.

Upon emergency evaluation at the hospital, medical staff proposed placing him on a breathing machine and inserting a tube into his chest cavity to drain off the excess fluids. In this way they felt they could stabilize his condition, and perhaps even allow him to return home again for a short time. Given this hope, his wife agreed to the treatments proposed and all proceeded as planned.

However, it was unexpectedly difficult to wean Joseph away from the breathing machine. He was quite weak from the cancer and he had difficulty regaining the strength to breathe on his own. Further, the fluids continued to accumulate for a time in spite of other treatment efforts. Even so, it was not long before he was awake and apparently alert. However, he remained unable to communicate (he was too weak to write, and no one can speak with a breathing tube in place as it must pass between the vocal cords on its way into the lungs, and thus it prevents any speech).

*Conclusion:* Finally, nearly two weeks later Joseph was successfully weaned away from the breathing machine and the tube was removed. It was at this moment that he kindly but firmly chided his wife, saying, “What did you put me on that machine for? I was totally out of it and I was comfortable after I passed out. Now I’ve got to go and die all over again!” At this his wife tearfully apologized, noting that she simply did not know what he had wanted, as he had never told her anything in advance and had not put anything in writing.

Now, again, would you want to be terminally ill and have to “die all over again”? Would you want a loved one struggling over the consequences of knowing they had made a clearly wrong choice in retrospect? Would it be any better if they only wondered if they’d made a wrong choice, simply because they never had the chance to review it with you in advance? Again, these are among the possible outcomes of the “do nothing” approach.

### ***Option 2. Tell Others of Your Wishes But Put Nothing in Writing***

Another option is to verbally share your wishes, but to put nothing into writing. In this way neither you nor your loved ones are bound to any written statement of your wishes, but your loved ones will still have at least some idea of what you might want done. To more fully evaluate this option, let us again look at some actual case examples of people who chose this approach.

Case Example C: Nancy Beth Cruzan was a 33-year old woman who sustained severe brain damage following an automobile accident in January, 1983. Her parents, watching their daughter over the next four years, found no hope that she would ever regain consciousness. Thus they requested that hospital staff stop all life sustaining treatments – including feeding tubes. This request was denied by the hospital. Therefore, her father petitioned the courts in 1987 for removal of her feeding tube.

At the lower court hearings the family presented evidence that Nancy had previously made explicit statements that she would never want to be kept alive as a “vegetable.” However, litigants for the state argued that this did not constitute sufficient evidence that she would want to specifically refuse tube feeding. The petition was not granted.

The case was appealed repeatedly and at great expense until it finally reached to the United States Supreme Court. There it was ruled that there *was* a constitutional right to refuse medical care, including feeding tubes, that might otherwise be imposed upon a person’s physical body. But it was also ruled that the states could require “clear and convincing evidence” of an individual’s wishes before life-sustaining treatments could be stopped.

The family diligently labored to gather further evidence of Nancy’s desires from relatives, friends and coworkers. Finally, three years after the court battles had begun, it was at last ruled that sufficient evidence did exist and Ms. Cruzan’s feeding tube was removed on December 15<sup>th</sup> and she died on December 27<sup>th</sup>.

It is important to emphasize here that *not a single family member, relative, friend or coworker ever presented any evidence against the parents’ request, nor were their efforts to remove the feeding tube opposed by anyone other than representatives of the hospital and the state.* All immediate family members, extended relatives and friends were in complete agreement that Nancy would not want her life continued in a permanently comatose condition by any artificial means. Yet, even with no family members or friends opposing this action it still took many years and an extended array witnesses to finally accomplish Nancy’s wishes. This, because she had not left anything in writing, and the state required “clear and convincing evidence” – the highest evidentiary standard in civil law.

*Conclusion:* Would you want your family to have to go through such a legal process in your behalf? Have you left sufficient evidence of your wishes, whether for or against such treatments? Are there enough people, with enough personal, first-hand information from you to be able to serve as witnesses of your wishes? Can you be sure that you’ve given them enough information to meet a “clear and convincing” standard of evidence? Will they even remember what you have told them? Will they press for your wishes to be honored even in the face of opposition? Should they, given the fact that you have left them with no evidence to present beyond their word alone? What if they must face suspicions of acting out of a desire for monetary or other secondary gain? Is there *anyone* in your extended family who might actually oppose your wishes for *any* reason?

These are the unavoidable concerns that arise from a selection of the “tell only, write nothing” option.

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Case Example D: On January 16, 1987, Michael Martin sustained severe brain injuries from an automobile accident. These injuries left him unable to speak and bed-bound. He was also left dependent on a “colostomy” (a bag attached to the abdomen) for bowel and bladder needs, and he required tube feeding to meet his nutritional demands. Five years later, in 1992, when no improvement had been realized, Michael’s wife, Mary, sought to have the feeding tube withdrawn. In this case the hospital supported her decision, but Michael’s mother and sister remained opposed.

The wife and two coworkers were aware of prior specific statements from Michael that he would not want to be kept alive in a condition of this nature, and testified of this in court. Michael’s sister also acknowledged that he had previously stated he would not want to be kept alive by use of a breathing machine if he were ever in a permanent coma. Further testimony from the wife offered in court included the following:

“Discussions between Mike and me regarding what our wishes would be if either of us was ever involved in a serious accident, had a disabling or terminal illness or was dying of old age, began approximately eight years ago. These discussions occurred on many different occasions. ...several were triggered by movies which we saw together. Mike's position was always the same: he did not want to be kept alive on machines and he made me promise that I would never permit it.”

Further:

“Some of the conversations...occurred after we watched movies about people who no longer were mentally competent either due to illness, accident or old age; others involved people who could no longer do anything for themselves, such as persons who lived in a nursing home and could no longer feed or dress themselves and needed to wear diapers or have other measures taken to continue existing. Mike stated to me on several occasions: ‘That's b\*llsh\*t, I would never want to live like that.’ He also said to me, ‘Please don't ever let me exist that way because those people don't even have their dignity.’ I always agreed with Mike because I felt the same way.”

Still further:

“One movie that always triggered such discussions was ‘Brian's Song,’ which, I recall, is a movie about a football player with a terminal illness. Mike said to me after we saw it together: ‘If I ever get sick don't put me on any machines to keep me going if there is no hope of getting better.’ He also said that if I ever put him on

machines to keep him alive: 'I'll always haunt you...' Then he would say, 'Do you understand?' I always said 'yes.' We watched this movie at least two or three times and had virtually the same discussion each time."

And still further:

"Mike was an avid hunter and frequently expressed concerned [sic] about a hunting accident. Mike frequently told me that if he ever had an accident from which he would 'not recover' and 'could not be the same person,' he did 'not want to live that way.' He would say, "...promise me you wouldn't let me live like that if I can't be the person I am right now, because if you do, believe me I'll haunt you every day of your life.' I stated my promise to him and made him promise me the same."

And yet further:

"Mike also made a lot of comments to me about never wanting to live 'like a vegetable.' He said that if anyone had to live like a vegetable, 'their families and doctors should be shot for forcing someone to live like that.' He would say, 'I'd be p\*ssed if I had to live that way.' He also told me that he believed it was unfair to the person who had to be kept alive on machines because that person would always be in pain. He told me that 'no one should have to be kept alive if they would never get well again.' "

After nearly a month of hearing such testimony, the court ruled that there existed "clear and convincing evidence" that Michael would not want to be kept alive in this condition. The trial court further ruled that removal of the feeding tube was in Michael's "best interests." However, the court still denied the petition. It cited the fact that Michael had not put his wishes in writing, and the fact that he was not immediately "terminally ill."

A court of appeals next heard the case, with further evidence from expert witnesses regarding the irreversible nature of Michael's condition, and the evidence as to what Michael would have wanted. The court of appeals agreed that there was sufficient evidence of Michael's wishes. However, the extended family members still opposed this decision, and it was next heard by the Michigan State Supreme Court.

In 1994, the state supreme court issued its ruling. The justices specifically cited the opposing counsel's argument in their ruling, which argument stressed that, "*assuming*" the family's statements "are *truthful* representations," the statements "*if truly made*" by Michael, were nevertheless "remote in time and place from his present circumstances. At the time the remarks were *supposedly* made, Michael was young and healthy. The remarks were general, vague and casual, because Mr. Martin was not presently experiencing and likely never had experienced the form of 'helplessness' he supposedly disliked, and thus, he could



not bring to bear his specific views about specific circumstances of which he was intimately knowledgeable. Not being informed by his actual experience, Michael's *purported* remarks thus were 'no different than those that many of us might make after witnessing an agonizing death of another' ” (*italics added*).

The court then further elaborated, “We are not satisfied that the evidence [given in testimony] is ‘so clear, direct and weighty and convincing as to enable [the fact-finder] to come to a clear conviction, without hesitancy, of the truth of the precise facts in issue’” (*quoting from Cruzan, 497 US 285, n 11*). The court then ruled that “the clear and convincing evidence standard has not been satisfied,” and summarily denied the petition.

*Conclusion:* In spite of the explicit nature of the statements Michael had previously made (which were clearly seen by opposing litigants as potentially fraudulent, too casual, and even irrelevant), it was ruled that there was insufficient evidence of his wishes. The problem largely persisted because “Michael's intentions...were not expressed in writing.” Again, this is one potential consequence of the “tell only, write nothing” approach.

Case Example E: Finally, consider the case of Theresa “Terri” Schindler Schiavo. In February of 1990 at the age of 26, Terri reportedly collapsed at home. Because she was being treated for bulimia (an eating disorder), it was suggested that a related potassium imbalance may have caused her heart to stop. Regardless, Terri suffered severe brain damage from a lack of oxygen, and was left unable to eat, walk, or talk, and required tube feeding to survive.

In 1991 her husband, Michael Schiavo, flew Terri to California for experimental therapy. However, the therapy produced no measurable success. He also moved her at times from one nursing home to another in search of better rehabilitation and care. For the first three years accounts indicate that Michael remained very involved in his wife's care and that he and her parents, the Schindlers, enjoyed an amicable relationship.

However, the amicability apparently ended in 1993, shortly after Michael won a \$1.3 million malpractice settlement over the treatment of Terri's potassium imbalance. \$750,000 was awarded in Terri's name and for her care. The rest was awarded to Michael for his loss of spousal consortium. Michael claims that in February 1993 Terri's father came to him and requested “his share” of the award. Michael allegedly declined, stating that the funds were to be used for Terri's care. Terri's father disputes this account, stating he had only requested access to Terri's funds to further her rehabilitation, which he claimed Michael was no longer pursuing.

Later, in July 1993, Terri's parents tried to have Michael removed as guardian and themselves appointed in his stead. They alleged poor care by Michael, and also voiced suspicions that he may have tried to strangle her. They speculated that this, rather than the potassium imbalance may have been the cause of her original injury. They further alleged that Michael was the source of Terri's

bulimia, noting that Terri had been ‘heavy’ in high school and was extremely self-conscious about her weight. They claimed that Michael had pressured her to stay thin with statements such as, “If you ever get that fat again, I’ll divorce you.” Michael denied the allegations of assault and also claimed he never made such disparaging threats. The case was ultimately dismissed.

When Michael became engaged in 1998 to a woman who was eventually to become his second spouse, and with whom he had fathered two children, the Schindlers again sued for guardianship based upon grounds of adultery and renewed allegations of neglect and abuse. Their efforts continued to fail.

By many available accounts, Michael remained a devoted husband and was noted by some to be found more frequently at the bedside than Terri’s own family. Yet, there was no discounting the considerable efforts being put forth by the Schindlers. In particular they were devoted to Terri’s continuing rehabilitation. This aroused considerable controversy, as some felt that the therapies they pursued could cause unnecessary disruption and potentially do more harm than good. Eventually Michael sought to prevent Terri’s parents from further involvement in this regard, to which they responded by securing covert “telephone ‘tough love’ rehabilitation” when they were denied other options.

As the years passed Michael became convinced that Terri’s condition would not improve. Acting upon statements he claimed Terri had made to him in the past he petitioned the courts for removal of her feeding tube. He testified, in part, that in a conversation about a disabled uncle Terri had told him never to prolong her life in a severely disabled condition. A girlfriend of Terri’s provided additional supporting testimony. Thus, on February 11, 2000, 10 years after Terri’s original collapse, a circuit court judge approved the request.

The parents sued for an injunction. They cited prior statements from Terri, her religious beliefs, and their belief that she was not truly comatose and could yet improve as injunctive grounds. They also produced testimony from a woman who had dated Michael between 1992 and 1993 who claimed to have once asked him what he knew about Terri’s wishes. She stated that he had responded, “How the hell should I know? We never spoke about this. My God, I was only 25 years old. How the hell should I know? We were young. We never spoke of this.” Finally, they alleged that Michael only wanted the feeding tube removed because he wanted to preserve the remainder of the malpractice award.

Over the next five years, a total of six court battles and multiple investigations ensued. Ultimately, 33 experts were sought out by the Schindlers to support their claim that Terri was still aware, able to communicate, and might yet benefit from rehabilitation. Multiple counter-opinions were obtained from other experts by the Schiavo legal team, as well.

By some reports, over half of the total funds awarded for Terri’s care were ultimately spent on legal fees. A legal defense organization temporarily covered the Schindler’s considerable legal costs for some two years, followed by additional funds and representation from a religious legal group.

One businessman offered Michael Schiavo \$1 million to walk away from Terri, and a “pledge fund” was set up for a similar purpose which claimed \$6 million in donations. Michael promptly and consistently declined any such offers.

Equally devoted right-to-die groups took up Michael's cause and condemned legal and government intrusions. The television media picked up the case along with the family's disputes, which resulted in endless news reports and culminated in appearances by Michael Schiavo on “Larry King Live,” and Terri's sister on “Oprah.”

Over the years Terri's feeding tube was repeatedly removed and reinserted, depending upon the current court orders. During one period of removal the Florida governor's office received upwards of 165,000 e-mails from a petition drive, requesting that the governor intervene. Calls also came from disabled rights activist Joni Tada, from actor Mel Gibson, from Focus on the Family founder Dr. James Dobson, and from the Vatican.

The result was “Terri's Law,” passed in October 2003, which allowed Gov. Jeb Bush and the Florida Attorney General to step in. The ACLU enjoined these efforts, and the Florida Supreme Court eventually struck down the law. In the Spring of 2005, state and federal congressional hearings were held and various bills proposed and passed. In March of 2005 the 11th Circuit Court of Appeals, the Florida State Supreme Court, and the United States Supreme Court either denied appeals or refused to further intervene.

Eventually Terri's husband prevailed and her feeding tube was removed. On March 31, 2005, she died with Michael at her beside. After Terri's death a much awaited autopsy was performed. The results: profoundly severe atrophy (withering away) of the brain, reduced to half its normal size; cortical blindness; findings consistent with a diagnosis of “persistent vegetative state”; irreversible damage that no amount of therapy could correct; and, finally, no evidence of strangulation or other neck injury.

However, controversial to the end, the Schindlers issued a statement on the autopsy, noting it confirms that “Terri was not terminal, *that Terri had no living will*, that Terri had a strong heart, and that Terri was brutally dehydrated to death” (*italics added*). An attorney specializing in “medical ethics cases” pointed out her belief that, “The frontal temporal and temporal poles and insular-cortex demonstrated relative preservation,” and concluding by saying, “What this tells us is that her cortex retained function and that her brain was more normal in the area that controls higher-level thinking.”

After all this, perhaps the last word came from Michael Schiavo. On Terri's grave stone he had engraved the words, “I kept my promise.”

*Conclusion:* There is much to learn from this case example. Failing to make your wishes openly known, particularly in writing, can pull your family apart and can cost you and your loved ones untold burdens in suffering, financial expense, public airing of private lives, and emotional burdens beyond measure. It is possible that both parties to the litigation were “right” in that they believed in

what they were doing. Money, remarriage, attachment, divergent religious views, and disagreements over recollections of statements can lead to very different perspectives. Where this occurs, great sorrow and even outright injustices can be carried out by otherwise well-meaning participants. Again, this is one possible result of the “tell only, write nothing” approach.

### ***Option 3. Putting Your Wishes in Writing and Appointing a Representative***

As can be seen, great problems often arise when one’s wishes are either incompletely known or entirely unknown. Yet, perhaps the most insidious travesties may arise when one’s wishes were never expressed. Although there may not be any open contention for or against any particular choice, the decisions made by others can still result in outcomes you would not want – by either allowing your premature demise or by permitting you to be kept alive in situations that involve long term suffering, graphic debilitation, and significant family burdens. Thus, your silence certainly offers no guarantee that your wishes will be honored nor that your family will be protected from the hardships that may otherwise be unwittingly imposed.

However, verbal expressions alone offer little more support. Questions about your personal intent, the applicability of your statements to any immediate circumstance, and the ultimate evidentiary capacity of the words you chose (and only as belatedly recalled by others) are inevitable. Further, your loved ones may be challenged, virtually accused of lying, humiliated and cross-examined, and may have their personal lives laid bare in a due-diligence search for any possible evidence of personal gain or character defect (whether real or imagined), and any personal or family history that might cast them as less than believable and honorable witnesses. All this may then be made public.

Far better for you to document your key desires thoroughly, methodically, and comprehensively, and for you to personally appoint a representative decision-maker to act in your stead. In this way you can avoid abandoning your family to the conflicts that may unfold in any competing efforts to support and honor an uncertain understanding of your wishes.

### **Summary**

It has been noted that nearly seventy percent of Americans will, at some point in their lives, have to decide to continue or withdraw life-supporting treatment for a loved one (*see The Elder Law Journal. 1999;7(1), p.155*). Clearly, the likelihood that a someone may yet need to know something of your personal wishes is substantial.

We are therefore pleased to offer you a superior advance directive that comprehensively and methodically covers all significant health care issues found to be of importance to a majority of the general public. The document is available as a comprehensive “Discussion Guide” for those still debating whether or not to put their wishes in a written legal format. It is also available as a “Representative Directive” for families currently facing the need to complete advance planning for a loved one who has already lost capacity. In this regard, one state’s

Supreme Court has emphasized that without *advance* decisions for an incapacitated loved one, life-sustaining treatments must *always* be used, or at least begun, as “there will be no time to get...authorization [to withhold them]...once an emergency arises.” The court therefore found that failing to make *advance* decisions amounted to “a decision by default” (*In re Guardianship of Grant*, 109 Wash.2d 545, 747 P.2d 445 (1987)). Thus, it is far better for families to come together, well in advance to make carefully considered and heartfelt choices in the best interests of someone they all love. The Representative Health Care Directive will aid in accomplishing this with a minimum of confusion and decision-making neglect.

Regardless of which document best serves your needs, you are encouraged to act promptly, to ensure the highest quality care for yourself and to protect the well-being of those you love.

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Lifecare Directives, LLC  
5348 Vegas Drive, #11  
Las Vegas, NV 89108  
(877) 559-0527  
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