Loving Conversations: A Seminar To Assist Hispanic Families in Advance Planning For Their End-Of-Life Care at El Divino Salvador Presbyterian Church And Monrovia Seventh-Day Adventist Church

Edgar Enrique Urbina

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ABSTRACT

LOVING CONVERSATIONS: A SEMINAR TO ASSIST HISPANIC FAMILIES IN ADVANCE PLANNING FOR THEIR END-OF-LIFE CARE AT EL DIVINO SALVADOR PRESBYTERIAN CHURCH AND MONROVIA SEVENTH-DAY ADVENTIST CHURCH

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ABSTRACT OF DOCTOR OF MINISTRY PROJECT

Project Dissertation

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Problem

Advanced technology is currently available to prolong life, but often there is a lack of preparation or documentation of the family and family wish for end-of-life care. It has been estimated that between 18 percent and 30 percent of Americans have completed an advance directive. The percentage drops even further among Hispanics. Advance planning on end-of-life care is a process people can use to prepare themselves and their loved ones for dying. The purpose of the project was to develop and evaluate the participants’ response to a seminar to encourage family conversations among members of Hispanic churches on practical preparations for end-of-life decisions within the context of Christian stewardship.
Method

Competent adults, sixty years of age or older who are members of the El Divino Salvador Presbyterian Church and the Monrovia Seventh-day Adventist Church were invited to participate in the seminar. The Loving Conversations Seminar consisted of three one-hour sessions. The participants were asked to complete a pre-test on the first session and post-test at the final session.

Results

The seminar was effective in achieving 100 percent participation among the subjects in expressing their end-of-life wishes to their loved ones. There was an increase of 20 percent in the completion rates of power of attorney for health-care and in living will advance directives documents.

Conclusions

Advance care planning for end-of-life care is a complex process that involves the person's values, faith, spiritual needs, knowledge, and concern for others. According to the participants of the seminar, a key motivator in expressing their end-of-life wishes to the family is to relieve their loved one from having to make difficult decisions on their behalf without knowing the person's end-of-life care wishes.

From a Christian's perspective, the most important thing a person can do on the issue of advance care planning is to accept Jesus as his/her personal Savior. To know Jesus as one's personal Savior brings peace and the assurance of eternal life.
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A project dissertation presented in partial fulfillment of the requirement for the degree Doctor of Ministry

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This dissertation is dedicated in love to:

My wife, Rumy who has been my support in my ministry and in my academic journey;
my children, Edgar and Becky whom I hope to inspire to pursue their goals and dreams;
and to my mother, Zoila who has been my inspiration in my academic journey.
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my Doctor of Ministry project.
CHAPTER I

INTRODUCTION TO THE PROJECT

Advance Care Planning

Developments in medical care and technology have added to the complexity of decisions associated with end-of-life situations. End-of-life decisions may involve cultural values, family dynamics and access to services and financial issues. Advance care planning is a process that provides a method for people to collaborate with family and others to prepare themselves and their loved ones for future end-of-life care decisions. It is a complex process that involves a person's values, faith, spiritual needs, knowledge and concern for others.

Advance directives are an important element of advance care planning. They are used throughout the United States as a way to identify preferences for life sustaining care for use when patients have lost their decision-making ability and also as a framework for decision-making as the end of life nears.

From a Christian perspective preparation for death is an important part of life. Advance planning for end-of-life care involves applying Christian principles to the discussion of the values and end-of-life wishes with family, friends and physicians.

Purpose

The purpose of this project was to develop and evaluate the participants' response
to the Loving Conversation seminar at El Divino Salvador Presbyterian Church and the Monrovia Seventh-day Adventist Spanish Church, in Los Angeles, California. The seminar encouraged family conversations on practical preparations for advance care planning and end-of-life decisions within the context of Christian stewardship.

**Statement of the Problem**

Advanced technology is currently available to prolong life, but often there is a lack of preparation or documentation of the patient’s and family’s desire for end-of-life care. As a hospital chaplain, I have been called to provide emotional and spiritual support to the families of comatose patients who are struggling with the decision of whether to keep their loved one on the ventilator and feeding tubes or withdraw their life support system. They usually do not want to be the ones responsible for making the decision to “unplug their loved one” and by this decision pronounce a death sentence.

In end-of-life situations, family members are frequently asked by the medical team what they want to have done. However, the family members may not fully understand what treatments are appropriate in a given situation. Decisions regarding levels of resuscitative efforts, feeding tubes, use of dialysis, and use and termination of mechanical ventilation can pose difficult dilemmas. Use of “do not resuscitate” terminology may cause families to feel guilt that they are not doing everything possible to maintain their loved one’s life.

A review of the literature suggests that between 18 percent and 30 percent of Americans have completed an advance directive.\(^1\) However, research published in April

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2010 using data from survey proxies in the Health and Retirement study found that 67.6 percent of adults, sixty years of age or older, who had died between 2000 and 2006 had completed advance directives. These percentages do not hold true for all segments of the population. The completion of advance directives is low among minority groups. H. B. Degenholtz et al. found that Hispanics were about one-third as likely as Caucasians to have living wills.

**Justification for the Project**

Hispanics, accounting for 15 percent of the U.S. populations, are the largest ethnic minority group in the United States, a proportion that is projected to increase to 30 percent by the year 2050. The U.S. Census Bureau estimates that 97.8 percent of the population in East Los Angeles and 34.3 percent in Monrovia, CA are Hispanics. A sample of convenience from one congregation in each of these areas was selected as test sites to conduct the seminar. El Divino Salvador Presbyterian Church is located in East Los Angeles, California and Monrovia Seventh-day Adventist Spanish Church is located in Monrovia, California.

It is commonly understood that death requires preparation, education, and...
support, as well as special attention to the needs of the family. This care has particular application to Christians and their understanding of stewardship. Christian stewardship is about making choices and how those choices affect us and others. Advance care planning and expressing the wishes for the end-of-life care is part of good stewardship.

Vital decisions such as beginning a potentially life sustaining treatment to prolong life or to withdraw a life support system that is postponing the moment of death belong ultimately to individuals with counsel and support from others. The Loving Conversations seminar introduces Hispanic church’s members to the significance, from a Christian perspective, of advance directives, organ donation, and other end-of-life issues.

**Description of the Project**

To prepare for this project a survey of the literature relevant to the general topic of advance care planning and end-of-life care was conducted. The project included a biblical overview and a practical theological reflection on death and dying and issues related to end-of-life care. The target audience was competent adults members of El Divino Salvador Presbyterian Church and Monrovia Seventh-day Adventist Spanish Church who are sixty years or older and understand the nature, extent, and probable consequences of their health-care decisions.

The seminar consisted of three one-hour sessions. The focus of the first session was on advance planning for end-of-life care as part of Christian stewardship. The second session dealt with how to have a caring conversation with the family about end-of-life issues. The last session provided opportunity for sharing and feedback and to evaluate the seminar.
Expectations from the Project

Following were the project expectations:

1. Educate Hispanic church’s members on the significance of advance directives, organ donation, and other end-of-life issues.

2. Provide tools on how to engage in meaningful conversations with the family about end-of-life issues and wishes.

3. Emphasize advance planning for end-of-life care as good Christian stewardship.

4. Provide instructions on how to designate a Health Care Agent to ensure that the end-of-life wishes will be honored.

5. Provide data that will be useful for recommendations for future seminar implementation.

Definitions of Terms

Advance Care Planning

Advance care planning is the process of discussing, determining and/or executing treatment directives, and appointing a proxy decision maker.

Advance Directives

An advanced directive is a legal document mentally competent people write to help guide their future medical care decisions in advance of a time when they may no longer be able to directly communicate their wishes. California is one of the very few states that allows organ donation to be part of the advance directive document. California
recognizes two types of advance directives: Living Will and Power of Attorney for Health-Care.

Artificial Feeding and Fluids

Artificial feeding and fluids is the term used when doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive. Artificial feeding is a way of getting calories and nutrients into the body when a person cannot eat naturally. It may involve the use of a tube inserted into the stomach through the nose, or inserted surgically through the skin and stomach wall. The tube can deliver nutrition, fluids, and medications.

Brain Death

Brain death is the irreversible end of all brain activity including involuntary activity necessary to sustain life due to total death of the cerebral neurons following loss of blood flow and oxygenation. Difficulties with ethics and decision making may arise if it is not made clear to the family that brain death is equivalent to death.

Cardiopulmonary Resuscitation (CPR)

Cardiopulmonary resuscitation (CPR) refers to medical procedures used to restart a patient’s heart and breathing when the heart stops beating and/or the lungs unexpectedly stop working. The medical team presses on the chest to help pump blood, and uses artificial breathing. Artificial breathing means the doctor puts a tube in the windpipe. A machine breathes for the patient through the tube. Patients often need an electrical shock to help restart the heartbeat. Without CPR, the heart will unlikely start beating again and the patient will probably die.
Comfort Care (Palliative Care)

Palliative care refers to care directed toward the quality of life of patients who are facing a life-threatening illness. Particular attention is given to the relief of pain and other symptoms including the patient’s psychological and spiritual needs. Special attention is given to provide support for the patient and the family.

Do-Not-Resuscitate (DNR) Order

DNR (Do Not Resuscitate) order states that no effort, such as CPR should be made to save the patient’s life if the heart stops beating or if the person stops breathing. The DNR tells the physician and other healthcare professionals that the patient is ready to accept death and that additional life-saving intervention is not desired.

End-of-Life Care

End-of-life care is the support and medical care given during the time surrounding death.

Health-Care Agent

A health-care agent is an individual (also called the surrogate or the proxy) who makes health care decisions on behalf of the patient when he/she cannot speak for himself/herself.

Hospice Care

Hospice care is a care approach available to a person who is terminally ill (death likely within six months). Its focus is not on curing the illness, shortening or prolonging life, but on the comfort and quality of life. Care focuses on symptom and pain.
management, keeping the person comfortable, and providing psychological and spiritual support to the patient, family, and caregivers.

Life Support Treatment

Life support treatment is any medical procedure, device, or medication to keep the patient alive. Life support treatment includes: medical devices put in to help the patient breathe, food and water supplied by medical device (tube feeding), cardiopulmonary resuscitation, major surgery, blood transfusions, dialysis, and anything else meant to keep the patient alive.

Living Will

A Living Will (officially called “Instructions for Health-Care in California) is a legal document that tells the doctor or other health care providers whether or not the person wants life-sustaining treatments or procedures administered if she/he is in a terminal condition or a permanent unconscious state.

Organ Donation

Organ donation is the process of removal and transplantation of viable organs from donor to recipient. Organ donation from one person can enhance the lives of fifty other people. Organs that can be donated include: heart, kidneys, pancreas, lungs, liver, and intestines. Tissues that can be donated are: cornea, skin, and bone marrow. To be transplanted organs must receive blood until they are removed from the donor’s body. Therefore, it may be necessary to place the donor on a breathing machine temporarily or provide other organ-sustaining treatment. The body of an organ donor can still be shown and buried after death.
Persistent Vegetative State

As defined by the American Academy of Neurology “a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiologic sleep/wake cycles but at no time is aware of himself/herself or the environment.”

Power of Attorney for Health-Care

The Power of Attorney is a legal document that designates one or more persons to act as a proxy decision maker if he/she should become temporarily or permanently unable to make those decisions.

Terminal Condition

In most states, a terminal condition is a status that is incurable or irreversible and in which death will occur within a short time.

Limitations of the Project

The project is limited to the church members from El Divino Salvador Presbyterian and the Monrovia Spanish churches who attended the Loving Conversation seminar. The project was conducted in Spanish. The results obtained from the participants of the seminar may not be generalized to other institutions, churches, or ethnic groups.

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CHAPTER II

A THEOLOGICAL REFLECTION ON DEATH AND DYING
AND ISSUES RELATED TO END-OF-LIFE CARE

Introduction

In the context of grief and despair following the death of Lazarus, Jesus not only shed his own tears, but also brought a theological perspective to the situation. "'I am the resurrection and the life. He who believes in me will live, even though he dies; and whoever lives and believes in me will never die. Do you believe this?' And Martha answered, 'Yes, Lord, I believe that you are the Christ, the Son of God, he who was to come into the world'" (John 11:25-27, NIV).

Jesus' statement recognizes the reality of death, but also the truth that death is not the final statement. God has the last word and that word is the foundation for the Christian reflection on a theology on death and dying. Ray Anderson, in his view on God's action in human history, defines Christian theology as "a reflection upon the meaning of God’s action in Jesus Christ"¹ and practical theology as "the reflective process in which the church pursues in its efforts to articulate the theological grounds of practical living in a variety of areas such as work, sexuality, marriage, youth, aging, and

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death."² It is the purpose of this chapter to reflect on the practical theological issues associated with death and dying. Focus will be given to the biblical context within the context of theodicy, the meaning of suffering, organ donation and the meaning of a good death. The last section of this chapter will deal with Christian perspectives on ethical decisions associated with care for the dying. This theological reflection has as its foundation the death and resurrection of our Lord Jesus Christ as the ultimate meaning and hope for our mortality.

**Clinical Perspective of Death**

For centuries, determining the death of another person was seen to be a straightforward matter. When a person’s heart stopped and the person’s breathing ceased, the person was declared dead. The introduction of the mechanical ventilator gave rise to the ethical and moral dilemma of determining when death occurs in a critical care setting. In 1959, French neurologists Pierre Mollaret and Maurice Goullon coined the term “beyond coma” for some brain-injured patients who were dependent on the ventilator to breathe. In their judgment, a patient who is “beyond coma” is not kept alive by the machine but, rather, is already dead. Their conclusion was that the mechanical ventilator is basically ventilating a corpse.³

**Brain Death as a Criterion of Death**

In 1968, a physician-led committee at Harvard Medical School proposed


irreversible coma (a permanently nonfunctioning brain) as a new criterion to define death. In the 1970s several state legislatures tried to turn this new criterion of death into a legally recognized standard for determining death. In 1981, the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research was charged with proposing a uniform statutory definition of death that could be adopted by all states of the Union. The result of the Commission’s effort was the Uniform Determination of Death Act, which holds, “An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brainstem is dead.”

The President’s Commission’s Determination of Death Act was endorsed by the American Medical Association, the American Bar Association, and the National Conference of Commissioners on Uniform State Laws.

Definitions of Death

Charles Culver and Bernard Gert argue that establishing the criterion for death is primarily a medical concern and defining death may be regarded as a philosophical task. Dr. Pellegrino summarizes the following four attempts to define death in philosophical terms:

1. Total Loss of Conscious Mental Capacity. Mental capacity is a fundamental

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capability specific to human life. A human body that can only function biologically without inward mental life does not sustain a moral agent.

2. Loss of somatic integration of the organism as a whole. A body which has suffered irreversible loss of all its executive power (brain activity or heart beating) can no longer function as an integrated whole and hence is no longer a living whole.

3. Loss of the capacity by patients for active spontaneous engagement with the environment through the function of breathing. The person lacking this capacity is said to be dead even if respiratory functions and cell metabolism are sustained by mechanical ventilation.

4. Separation of some vital principle from the body. Death is nothing else but the separation from the soul and body.

Theological Reflection on Death and Dying

It is not enough to describe death only in terms of the total stoppage of the circulation of blood and the cessation of vital functions or even as irreversible coma or brain death. Scripture defines another type of death. This is the death that human beings die as a consequence of sin. It is more than the result of biological death. The Bible also informs that death in any form is the antithesis to what God originally had in mind for his creation. When a person dies, the mental, spiritual, and physical experiences come to an end.

Pope John Paul II addressed the biblical teaching on death at the 18th International Congress on the Transplantation Society. Here, he described the relationship between the concept of death presented in the Bible and the medical concept of death presented by the Uniform Determination of Death Act.
The death of the person is a single event, consisting in the total disintegration of that unitary and integrated whole that is the personal self. It results from the separation of the life-principle from the corporal reality of the person. The death of the person, understood in this primary sense, is an event which no scientific technique or empirical method can identify directly. Yet human experience shows that once death occurs certain biological signs inevitably follow, which medicine has learnt to recognize with increasing precision. In this sense, the criteria for ascertaining death used by medicine today should not be understood as the technical-scientific determination of the exact moment of a person's death, but as a scientifically secure means of identifying the biological signs that a person has indeed died.7

Death, Complete Cessation of Life

The Scriptures depict death as a state of temporary unconsciousness. The Bible calls this intermediary step a sleep (Ps 13:3; Matt 9:24; John 11:11-14). There is, however, no part of a dead person that keeps going in some other mode of being. Immortality, despite claims to the contrary, is not part of the biblical narrative. Richard Rice suggests that the concept of natural immorality resonates with many people because of the instinctive revulsion that human beings feel toward death, and the concept of some immortal entity that comforts and reassures people when their love ones die.8

Death, a Defeated Enemy

The Scriptures, as noted above, indicate that death was not a feature of the original creation. It came as a result of Adam's fall. God, as he viewed his finished creation declared that all he had made was "very good" (Gen 1:31). Adam and Eve were introduced to the possibility of death as something negative that would result if they

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chose to disobey God. However, they succumbed to the temptation to disobey God, thus severing their relationship with him. This separation brought guilt, shame, physical pain, and, ultimately, death.

The author of Genesis records the entrance of death when God said to Adam and Eve, "... return to the ground, since from it you were taken; for dust you are and to dust you will return" (Gen 3:19, NIV). Paul, in the New Testament, posits that because of Adam's sin, death has passed to all people: "Therefore, just as sin entered the world through one man, and death through sin, and in this way death came to all, because all sinned" (Rom 5:12, NIV).

The Bible portrays death as an enemy (1 Cor 15:26). Consequently, we have the right to feel frightened and to fight against it. The touching scene of Jesus weeping at the tomb of Lazarus referenced above reinforces this negative view of death (John 11:35). He likewise expressed compassion for the grieving of the widow whose son had died (Luke 7:12-13). The horror he felt as his own death approached is a statement of his own view toward death. He pleaded that the cup be removed (Matt 26:37-44). Yet Christians praise God for the wonderful truth that although death is an enemy, it is a defeated enemy assured by the death and the resurrection of our Lord and Savior Jesus Christ.

When Paul, reflecting further on Jesus' death, tells the Christians at Thessalonica, "we believe that Jesus died and rose again and so we believe that God will bring with Jesus those who have fallen asleep in him" (1 Thess 4:14, NIV). He is stating a theology of death that came about through his pastoral reflection upon the meaning of death in light of the death and resurrection of Jesus Christ. Paul's teaching is that "the Lord himself will come down from heaven, with a loud command, with the voice of the
archangel and with the trumpet call of God and the dead in Christ will rise first. After that, we who are still alive and are left will be caught up together with them in the clouds to meet the Lord in the air. And so we will be with the Lord forever” (1 Thess 4:16, 17, NIV). It is this affirmation that provides believers the assurance that death does not have the last word. God will resurrect humans to a new life just as he resurrected Jesus.

The biblical view of death acknowledges the inherent negativity of death on one hand, but on the other, affirms the reality of a future beyond death. Michael Bartalos illustrates this tension as he describes the enduring cadences of separation and the fear of death as follows:

We can’t even apprehend death, let alone comprehend it, apart from our conscious and unconscious preoccupation with separation from others. For humans, death does not mean nothingness but separation, aloneness, isolation, and the end of vital contact with others, and it is always felt this way or experienced this way in the core of the self. Hence the great religious promise of eternal life boils down to the promise of no separation, no truncation of the ties that bind. God takes the parent’s place, and God is always there, forever.9

Death continues as a physical event in the temporal lives of Christians. However, the experience of physical death has no power to separate the believer from God. Christians do die, but this death is different from the death that occurs to those who do not belong to Christ. They are dead in Christ (1 Thess 4:16). The term “the dead in Christ” is used by Paul to distinguish the sleeping saints from two other classes of people: (1) the unrighteous dead, who, as bodies, are not raised at Christ’s second coming; and (2) the living Christians.10 To die in Christ, as the Apostle proclaimed, is to have one’s


entire life upheld by the life of the one who was born, who died, was resurrected and who continues to live beyond the power of death.\textsuperscript{11}

Christians and non-Christians alike experience sorrow, uncertainty, and pain in the face of death. As a chaplain, I have observed terminal patients, whether they are Christian or non-Christian, express their fears of the process of dying. They are often afraid of the pain and of being a burden to their families. Robert Neale illustrates this point when he quotes a patient who said: "In thinking about my own death, I have much greater problems with the idea of dying than on the idea of death itself. I have anxieties concerning a long day-to-day struggle to either live or die. I'm afraid it would feel cowardly not to fight for life in the face of a fatal illness and feel I would be constantly torn between wanting to make a brave fight and giving up."\textsuperscript{12} People are also afraid of death because death marks the end of all that is most familiar.

Christian doctrine views the restoring miracles of Jesus as God's intervention in history to remind us that the healing miracles are penultimate actions, designed to validate the expectation of the ultimate solution of all of life's problems in the resurrection of the dead associated with End Time events. Did not the people Jesus healed eventually die? And did not those whom He brought back from the dead experience death again? Now they, with all the rest of humanity, await the sound of the last trumpet. Ray Anderson is right when he states that the "quality of life cannot be determined solely by extending the biological life of human persons. The concept of life as revealed in the New Testament, particularly in light of the life which issues from Jesus

\textsuperscript{11}Anderson, \textit{Theology and Dying}, 139.

Christ, is participation in the life of God which is given to human persons by creation and extended through death by the redemption and life of Christ.”  

The biblical answer to the problem of death is found in the resurrection of Jesus. It is a victory for all persons who are related to God through Jesus Christ. The core of this Christian perspective is faith. Anderson points out that “it is faith in the God who has overcome death and who lives through Jesus Christ that enables Christians to surrender their time and history to God and to receive it back again from Him as the gift of life.”

Brevity of Human Life

The Scriptures emphasize the brevity or fragility of life and the frustration that accompanies it (Ps 90:10). James says that human life is as a “vapor that appears for a little time and then vanishes away” (Jas 4:14, NKJV), and the prophet Isaiah compares human flesh to grass, though it has a moment of beauty, eventually it withers and fades away (Isa 40:6-7). In the psalm associated with Moses, the author wrote: “Teach us to realize the brevity of life, so that we may grow in wisdom” (Ps 90:12, NLT).

This biblical view suggests two implications. First, since believers are aware that their time on this earth is limited and they do not know the exact time of death, they are responsible to make decisions that honor life and please God. Honoring life and pleasing God includes knowing when efforts to continue life are futile. As death draws near, believers do not have to fight unceasingly as if they could conquer death. Death will not be overcome until Christ returns.

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13Anderson, Theology, Death and Dying, 139.
14Ibid., 126.
Second, the believers’ anticipation of Heaven will motive them to intensive Christian service here on earth. As Paul reflects,

For to me, to live is Christ and to die is gain. If I am to go on living in the body, this will mean fruitful labor for me. Yet what shall I choose? I do not know. I am torn between the two: I desire to depart and be with Christ, which is better by far; but it is more necessary for you that I remain in the body. Convinced of this, I know that I will remain, and I will continue with all of you for your progress and joy in the faith (Phil 1:21-25, NIV).

Paul’s perspective on dying and being with Christ made him aware that his days were numbered. It motivated him to fill his days with work for the kingdom of God. This view inspired Paul to live his life faithfully, enduring the spiritual challenges along his way.

Preparation for the Dying Process

From a Christian’s perspective, the most important thing an individual can do to prepare for the dying process is to become personally acquainted with the One who came as a child in Bethlehem and accept him as his/her personal Savior. To know Jesus as one’s personal Savior will bring peace and the assurance of eternal life.

Another significant way a person can prepare for the dying process is to build and maintain healthy relationships with family members, friends, and church members. It is important to acknowledge that the dying process is not only the experience of an individual; it is the experience of a community. When death arrives, the family members miss the one who has died. They long to be with the person they loved; however, for a Christian, there is the assurance that the separation is only temporary. At the time of death, believers do not grieve like others who have no hope (1 Thess 4:13). Believers are consoled by the “blessed hope,” the hope of the resurrection.
Planning for Death Is Good Stewardship

The *Seventh-day Adventist Encyclopedia* defines stewardship as a person’s “responsibility for, and use of, everything entrusted to him/her by God including life, physical being, time, talents and abilities, material possessions, and opportunities to be a service to others and his/her knowledge of truth.”\(^5\) Paul writes to the Corinthians, “Do you not know that your body is a temple of the Holy Spirit, who is in you, whom you have received from God? You are not your own; you were bought at a price. Therefore honor God with your body” (1 Cor 6:19, 20, NIV). It is the biblical teaching that Christians are stewards of their bodies, health, and resources.

Stewardship is not limited to giving our tithes and offerings to the local church. It is about being faithful disciples, caring for and managing all that God has given us in all the stages of life. Christian stewardship is about making choices and how our choices affect us and others. Christians are stewards of their bodies, health, and resources. Therefore, believers are responsible to God for their life style and health care choices. This perspective suggests that stewardship at the end-of-life involves advance care planning regarding medical decisions that are based upon biblical principles.

I have observed in my ministry as a chaplain at White Memorial Medical Center major disagreements within the dying person’s circle of loved ones or between loved ones and health care providers when it comes to determining what course of action to take as time-of-death approaches. It has been estimated that nearly 40 percent of all deaths in the United States take place following the withdrawal of life-sustaining treatments, often from a sedated or comatose patient and after protracted, agonizing

\(^{15}\)SDA Encyclopedia, 1976 ed., s.v. “Stewardship.”
decisions on the part of family members and the medical team.\textsuperscript{16}

Disagreements about an incapacitated relative’s care may have a number of undesirable consequences for both patients and families. Qualitative research suggests that disagreements among a patient’s family members tend to result in more aggressive end-of-life treatment for patients and increases the likelihood that futile medical tests and treatments are administered and the dying process prolonged. An unfortunate consequence is that in many of these cases palliative care is postponed or never delivered.\textsuperscript{17} Advance directives are an effective method to assist the family as they confront the important issues associated with end-of-life decisions.

Advance directives are discussions or written statements which convey a person’s wishes to his or her family and physician in the event that the person becomes unable to discuss such matters. They are an important part of good stewardship. The utilization of advance directives has the potential to protect loving family members from agonizing decisions about end-of-life care. Prior to completing an advance directive, Christians should consider prayerfully God’s will for their lives. Family, pastors, and other Christian advisors may be of assistance to the person who is uncertain about the application of biblical principles to their particular situation. Dr. George Rutecki, a Christian physician, in addressing this matter writes,

Terminal care decisions must be free of any intention to cause death; they must never be used to eliminate suffering by eliminating the sufferer; they must address the moral issue of who is entrusted with treatment decisions for another; they cannot rely on quality of life determinations alone and must remain as clear as possible in the


differentiation between terminal and imminent. Such a distinction is essential so as not to lead to an early abandonment of medical interventions and should leave the door open later to the ministry of terminal care appropriate when attempts at cure are exhausted.¹⁸

Meaning of Suffering

A fifty-five year old Hispanic female patient was pronounced brain dead. The family decided to withdraw her from the life support system. As I entered the room, I immediately noticed the patient lying on the bed with the ventilator and other tubes attached to her fragile body. As I introduced myself as the chaplain on call, the family (three children and two siblings) looked at me and remained silent for a couple of minutes that at that time seemed to be a very long time. The eldest son broke the silence when he said: “I do not know why she has to die. She has been suffering for many years. My mother earned heaven because of her suffering. Why God? I’d rather give my life than to see her dying. Why God? Why her? Why not me?”

A nurse came and asked to talk with them. We went to another room. She introduced herself as the nurse from the Regional Organ Donation Agency. The nurse asked if the family was willing to donate some of the mother’s organs. I could sense a tension in the room. The older son was reluctant to make this decision while the other siblings were open to donate their mother’s organs. The son looked at me and said: “Pastor, is it OK to donate organs? Is she still alive?” The medical team had pronounced their mother dead but she continued to breathe with assistance from the ventilator. The nurse explained to the family the concepts of brain death and organ donation. Finally, the

family decided to share the precious gift of life to other human beings by donating their loved one’s organs.

Since the fall, humans have been subject to both pain and suffering. Suffering is a broad and mysterious experience that touches all aspects of who we are. It can involve the prolonged physical pain associated with illness and injury as well as the unrelenting anguish that accompanies mental, emotional, and spiritual conflict.\(^{19}\) Suffering is more than pain from the spread of cancer or shortness of breath from emphysema or weakness and fatigue from heart surgery. Suffering is part of the existential burden of knowing that our time is ending, facing the loss of independence and freedom that terminal illness often brings.

**Suffering Is a Mystery**

In Job’s story, he experiences the loss of family and health. His comforters are of the opinion he has done something that triggered these events. He denies the accusations. In this, one of the most ancient stories in the Bible, we find examples of the five most common responses when people experience personal tragedy. The first one is found in the dialogue between God and Satan, in the first two chapters of the book of Job: the idea that suffering occurs as a test to a believer. The three friends who came to comfort Job introduce the second response to the tension: the concept of Divine Retribution, in which God punishes sinners because of their sins.

Elihu, in chapters 32 to 37, makes the third response. He tells Job that some suffering is educational, a form of discipline. The fourth response, which can be found in

various places throughout the text, comes from Job himself. He argues that there is no explanation for what has befallen him. In his view, suffering is completely devoid of meaning, something that simply must be endured. The final response comes from the Lord. He speaks out of the whirlwind. The question, Why suffer? is left without an answer. The book closes with a list of questions. In them, God demonstrates our limited knowledge.

In this ancient story, suffering is a mystery in the sense that God alone knows all and decides justly in every situation, however odd and even contradictory at times the divine decisions may seem. The author of the book of Job is not satisfied with how Job’s friends respond to his desperate situation. He refutes the first, second, and third responses to the problem of suffering by showing God’s disapproval toward the four who spoke against Job. What is of interest about these three responses as they apply to the problem of suffering is that the author of the book dismisses every one of the points that the three friends direct to Job, first on logical grounds, and also for existential reasons; they do not seem to take the sufferer seriously enough. Job’s response is crucial because he was the one who was experiencing the crisis. As he experienced the crisis, his suffering, from his perspective, was completely devoid of meaning. What he experienced made no sense.

Burton Cooper makes the following point:

Job knows that his suffering is underserved. What he does not know is how it is possible for underserved suffering to occur. That question remains unanswered. But he does experience God’s holy and healing presence. He discovers that in the presence of God’s love, his complaints can find their resting place. His pain is stilled and he attains a state of mind in which there is no desire to ask about the justice of

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God. The experience of God’s love has proven sufficient to him. “Now my eye sees thee” (Job 42:5).\footnote{Burton Z. Cooper, *Why, God* (Louisville, KY: John Knox Press, 1988), 42.}

The final response states the case that suffering is a mystery. We may attempt to express a theological, personal, and ethical response to the question, Why suffering? However, the bottom line is that suffering is a mystery for the person who experiences the crisis and to those who observe. Yet, God’s response in the book of Job indicates that he does not forever remain aloof from a suffering person. John Stackhouse argues that whatever God spoke out of whirlwind was good enough for Job. In the first place, God did not leave Job alone forever in his distress. Second, whatever we might think of the inadequacy of God’s response, Job himself was satisfied with God’s presence and His transcendent wisdom. Third, God vindicated Job in the eyes of his companions, and goes on to tell them that they have slandered not Job, but God.\footnote{John G. Stackhouse, *Can God Be Trusted?* (Downers Grove, IL: InterVarsity Press, 2009), 110.}

**Ministering to the Sufferer**

Christian compassion calls for the alleviation of suffering (Matt 25:34-40). Christians are called to follow the model of Jesus. He reached out to suffering humanity and brought healing and relief to those who suffered. This model has particular application to the latter stages of life. Pain, suffering, and disability often confront people in their later years. These difficulties can challenge an individual’s faith, as well as that of his/her caregivers and friends. The religious counselor can play an important role in providing support for those who experience intense suffering and pain.

Eugene Peterson states that when a pastor encounters a person in crisis, the first
order of pastoral ministry is to “join the sufferer by entering into the pain, the hurt, the sense of absurdity and to descend into the depths.”

Marsha Fowler suggests the following three ways to minister to those who suffer:

1. To reclaim the tragic vision of life by understanding that suffering and death are intrinsic to life and are ultimately inescapable. Suffering is not ours to master and death is not a clinical failure or personal insult. Pastoral care involves meeting those who are suffering, and rather than fleeing, to walk into their suffering.

2. The horror of suffering resides in its sense of abandonment or forsakenness. Jesus cried out “My God, my God, why have you forsaken me?” (Matt 27:46, NIV). The only meaningful response to suffering is found not in doing, but in being, in intimacy with God and with others.

3. Involvement of the church as a Community of Shalom providing the sufferer as an individual with an environment of comfort, caring, and refuge.

Organ Donation

As the family, the nurse, and I were processing the issue of organ donation in the account described above, I thought that it was rude or perhaps too emotional for the family who was grieving the loss of their loved one for the nurse to be so blunt when she asked if the family might consider the mother as a donor. As I look retrospectively at this crisis, I realize I was perhaps reflecting some of my own pastoral uncertainties on this

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subject. Christine Gallagher, in her survey of clergy, seminary students, and chaplains, reports the findings of two questions on the issue of organ donation and grief.

The first question was, “I feel that organ donation is too emotional for a family to deal with when a loved one dies.” The results of this study showed that 75 percent of the people surveyed disagreed with the statement. The other question focused on whether or not those surveyed feel that organ donation can help with the grieving process. Students and chaplains agreed (84 percent and 86.1 percent respectively). Only 56.1 percent of the congregational clergy agreed with the statement. There were some that expressed a significant rate of uncertainty, 33.3 percent.25

Traditionally, Seventy-day Adventists have been very supportive of organ transplants. Dr. Leonard Bailey and Loma Linda University Medical Center in Loma Linda, California, have pioneered the field of infant heart transplants. Theological reflection regarding organ donation will focus on the love showed by God and recorded in John 3:16 (NIV): “For God so loved the world that he gave his one and only Son, that whoever believes in him shall not perish but have eternal life.” Jesus gave his life for humanity, so that people can enjoy the gift of life. The core of this theology is that life began as a gift. God breathed into Adam’s nostrils the breath of life. In that instant, God gave Adam the first and greatest gift. He gave his breath, and with it life. Later Adam himself played a part in extending the gift of life to another. “While he was sleeping, God took one of the man’s ribs and closed up the place with flesh. Then the Lord God made a woman from the rib he had taken out of the man” (Gen 2:21, 22, NIV).

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The Apostle Paul, in his letter to the Galatians, reminds the Galatians of how greatly they cared about Paul in his weakness saying, “if it had been possible, ye would have plucked out your own eyes, and have given them to me” (Gal 4:15, KJV).

According to the *Seventh-day Adventist Bible Commentary* the term “plucked out” reflects the Galatians’ devotion to Paul.\(^{26}\) In the first century, donating one’s eyes was not possible. However looking at this verse with the 21st century ability to use donated organs, it would seem to us that Paul would commend those who desired to donate their eyes. Paul’s statement suggests that our bodies are given to us by God to be used according to his will or in the terminology of Paul, “Christ will be exalted in my body, whether by life or by death” (Phil 1:20, NIV). The one who accepts this approach will conclude that if it is God’s will that we help someone by giving them an organ that God has given us, then Christ will be magnified.

A mother of a donor described her experience as follow: “We found discussing and making the decision to donate eased our pain. We were able to focus on the joy this donation would bring to others and began the grieving process. I consider it an honor and privilege to have given the gift of life to others.”\(^{27}\)

**Good Death**

Some people think of the ideal death as going to bed one night and simply not

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\(^{27}\)Gallagher, “*Hear a Just Cause, O Lord, Attend to My Cry*,” 217.
waking up. Most of us would probably define a “good death” as dying peacefully, possibly aware that we are near our end, having achieved most of what we wished to achieve in our lives. Our hope is that there will be no pain, either physical or emotional. We would certainly like to be like Moses, who though he did not go into the Promised Land, saw it from the top of Mount Nebo, and was “a hundred and twenty years old when he died, yet his eyes were not weak nor his strength gone” (Deut 34:7, NIV).

Elisabeth Kubler-Ross observed that people go through predictable stages as they deal with their own death. In her book *On Death and Dying* she says that most people begin to deal with their death by expressing anger. This is followed by bargaining, depression, and ending with a somber acceptance. Kubler-Ross implies that human beings have nothing to be afraid of because death is a natural part of life, to be pursued at the appropriate time. Theologian Helmut Thielicke argues that persons have a right to die as a function of the dignity of life that God has given them. Human dignity is not located essentially in the biological aspect of life, but in the human person as a God-given endowment of life.

*Euthanasia*

Etymologically, euthanasia comes from the Greek *eu* “good” and *thanatos* “death.” Literally it means a good death. Charles Corr and colleagues define euthanasia as a situation in which the intentions of the person who contributes to the death of the

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second person embody an attempt to end the suffering of that second person. They make the distinction between active and passive euthanasia as follows:

Actively doing something to end suffering by ending a human life is often called active euthanasia. The case is a bit more complex when we turn to passive euthanasia. One might speak here of foregoing some intervention which seems to include either not doing something or omitting some action that is necessary to sustain life. The first of these alternatives refers to withholding (not supplying) some intervention necessary to sustain life; the latter to withdrawing (taking away) some intervention that is currently in place and may be helping to sustain life. Withdrawing removes the obstacle that is or may be blocking the natural processes of dying.

The Seventh-day Adventist church rejects “mercy killing” as an unacceptable practice, even if its intent is to end suffering. However, Adventists hold that it is acceptable to permit a patient to die by withholding or withdrawing medical interventions that artificially extend human life. To withdraw or withhold medical intervention in order to extend life is morally different from actions that have as the primary intention the direct taking of a life. The Seventh-day Adventist position implies that the use of the term passive euthanasia is inappropriate and confusing. According to this view, it is desirable to limit the term euthanasia to situations in which one person acts to cause the death of another because acts of discontinuing treatment with the realization that patients will die of their disease do not constitute euthanasia. Instead, withholding medical intervention in situations where life would otherwise cease is consistent with the


31 Ibid., 492.

responsible care that medical personnel show toward patients that appear to have entered the process of dying.

Physician Assisted Suicide

Physician assisted suicide occurs when a physician helps a person take his or her own life by giving advice, writing a prescription for lethal medication, or assisting the individual with some device which allows the person to take his or her own life. Dr. Robert Orr makes the distinction between euthanasia and physician assisted suicide on the one hand and the decision to forego treatment on the other as follows:

The first difference is intent. The intention of euthanasia and physician-assisted suicide is death. When the decision is to forego treatment the intention is to stop prolonging the dying process. The second difference is in attitude: an attitude of control in the former and an attitude of humility and resignation in the latter. There is likewise a deference of means. In euthanasia and physician-assisted suicide, the means is killing. In the decision to forego treatment, the means is allowing one to die. There is a difference in agency. In the former the physician is the agent of death, but in the latter, the disease is the agent of death.3 3

The Sanctity of Human Life

The sanctity of human life is rooted in the creation of people in the image of God (Gen 1:26-27). Scholars disagree over the components that make up the image of God in humanity, but one thing is clear: Human beings have a value and a unique place above all other forms of life on the earth. God has invested people with sacred value. The Psalmist declares that human beings are made a little lower than the angels and are crowned with glory and honor (Ps 8:5). The Dictionary of Christian Ethics describes the sanctity of life principle as:

Derived from the doctrine of God as Creator. God has made man in his image with power to reason and the capacity to choose. Each individual is precious to him and made for eternal destiny. Thus the Christian attitude toward human life can only be one of reverence-enjoined by the whole of the Decalogue (not only by the Sixth Commandment) and confirmed by the incarnation—which is extended to every individual from the moment of his conception to extreme old age.34

God is sovereign over human life. Karl Barth says: “It is for God and God alone to make an end of life.”35 Paul says it this way: “for none of us lives to himself alone and none of us dies to himself alone. If we live, we live to the Lord; and if we die, we die to the Lord. So, whether we live or die, we belong to the Lord” (Rom 14:7-8, NIV). God himself is the giver and taker of human life (Job 1:21). Human beings do not possess ultimate authority over life and death.

The Bible does not mention the words suicide or euthanasia, but its teaching appears to condemn both suicide and euthanasia for the following reasons:

1. Since the Bible specifically condemns murder (Exod 20:13) and suicide is a form of murder, it is reasonable to conclude that the Bible also prohibits suicide;

2. Even the most desperate believer in the Bible who desired death, never considered suicide a morally valid option. Jonah’s prayer illustrates this point: “O Lord, take away my life, for it is better for me to die than to live” (Jonah 4:3, NIV).

3. The Scriptures record five cases of suicide: Abimelech (Judg 9:50-56), Saul and his armor bearer (1 Sam 31:1-6), Zimri (1 Kgs 16:18-19), Athithophel (2 Sam 17:23), and Judas (Matt 27:3-5). In each case of suicide recorded in Scripture, death represents a

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tragic end to a life that did not meet with God’s approval.\textsuperscript{36}

From the above, it can be conclude that from the biblical perspective euthanasia and physician assisted suicides are fundamentally wrong. Both involve the killing of human beings who are made in the image of God, and, in the Bible writers’ perspectives, this is murder and therefore prohibited. In the incarnation, God became a member of the human race, enduring suffering, and bearing our burdens. John Kilner and Ben Mitchel make the point that “if we are to exhibit true compassion, which literally means suffering with, we too, will be incarnational and do all we can to bear the burdens of dying patients with them. We will not get rid of the problems by getting rid of the patients.”\textsuperscript{37} This kind of compassionate care is a clear expression of agape love, that love that promotes the use of medications to relieve pain, provides human companionship, and gives opportunity for spiritual support.

**Spirituality, an Element of a Good Death**

Dr. John T. Dunlop states that it is difficult if not impossible to define a good death without a spiritual context. He identified the following principles that define a good death:\textsuperscript{38}

1. A good death is the natural trajectory of faith commitments made earlier in life. There should be no discontinuity between the faith we live by and the faith we die by. A believer finds ultimate value not in this life but in an eternal relationship with God.


2. A good death may require advance planning. This involves an in-depth discussion of the values and wishes with the family and the person appointed as the power of attorney. If a living will is used, it should be consistent with Christian values and faith.

3. A good death has completed relationships including those that need reconciliation. According to Dunlop, there are four things that need to be said as life comes to an end: I love you, thank you, I forgive you, and forgive me. These four statements may provide an occasion to reconcile relationships that have been broken.

4. A good death comes after we cease clinging to the things and values of this world and increasingly embrace eternity.

5. A good death is peaceful, for the dying person knows that it will lead to resurrection and eternal life in God’s presence.

John Booty, reflecting on the Anglican tradition, suggests the term “ars moriendi,” the art of dying well, refers to the tension in the Christian life between fearing death and welcoming it as a promise to eternal life. Dying well, according to Booty, is not a command to cure everything, but to care for those who are dying so that they may die well.39

Dying well includes spiritual care at the end-of-life. William Breitbart suggests that spiritual issues such as meaning/purpose and hope are increasingly identified as important by patients, family members, clinicians, and researchers. He states that spirituality includes faith and meaning. Faith addresses the religious aspects of

spirituality and meaning deals with either religious or non-religious aspects of spirituality.⁴⁰

Chaplain M. C. Wright provides a useful overview of what comprises the essence of spiritual care founded on the assumption that all people are spiritual beings. He states that spiritual care “recognizes the relationship between illness and the spiritual domain and acknowledges the possibility of a search for meaning of the big questions of life and death. Spiritual care responds to religious and humanistic needs by meeting both the requirements of faith and the desire for another being to be there.”⁴¹

For a Christian, death marks the completion of a task, a life of faithfulness that has come to its end. The apostle Paul expressed this concept when he reflects on the end of his life:

For I am already being poured out like a drink offering, and the time has come for my departure. I have fought the good fight, I have finished the race, I have kept the faith. Now there is in store for me the crown of righteousness, which the Lord, the righteous Judge, will award to me on that day—and not only to me, but also to all who have longed for his appearing” (2 Tim 4:6-8, NIV).

For Paul, dying well means that Christians faithfully endure the spiritual challenges along life’s journey. Then, at the end of their lives, they are prepared for the dying process. Christians look forward with hope to the day when God “will wipe away every tear from their eyes. There will be no more death or mourning or crying or pain, for the old order of things has passed away” (Rev 21:4, NIV).


Christian Perspectives on Ethical Decisions Regarding Caring for the Dying

Developments in modern medicine have added to the complexity of decisions about care for the dying. Today decision-making is much different than it was in the past. Historically, the attending physician was the one who made the medical decision based on what he or she believed was best for the patient. Now, as long as the patient is conscious and, in most states, over the age of eighteen, the decisions regarding medical treatment rest with the patient. If the patient is not conscious and has not expressed his/her wishes regarding end-of-life care, a health-care surrogate, usually a member of the family makes the medical decision based on what is believed to be best for the patient or what is consistent with the patient’s desire.

How People Make End-of-Life Decisions

People make decisions every day based on their training and experience without ethical reflection. However, when individuals come to decisions about their own lives as it nears its end, or when they have to make decisions for loved ones, they often ask, What is the right thing to do? People usually call upon a set of prior decisions, their moral and spiritual decisions and life experiences to arrive at a decision they believe feel to be correct.

When making end-of-life decisions for a human being it is important to understand and remember the beliefs, wishes and request of the dying person. Bruce Jennings is correct when he states that the health care surrogacy in end-of-life decision-making is both a cognitive and an affective task. It involves complex medical information, moral and religious ideas, probabilistic judgments, and deep-seated
emotions. The decisions a surrogate makes affect the surrogate himself or herself and the entire family.

Medical Issues in End-of-Life Care Decisions

Robert Cranston identifies the following complex medical issues facing patients, their families, and their treatment team as they make end-of-life decisions:

1. Should an intravenous line be placed to provide hydration and treatment?
2. Should a tube be placed to provide mechanical ventilation via the mouth or nose (intubation) or throat (tracheotomy)?
3. If a patient’s heart or respiration were to cease, should cardio-pulmonary resuscitation (CPR) be performed?
4. Should other major intervention (such as surgery, chemotherapy, or radiation therapy) be performed if the patient is unable to participate in the decision? This involves consideration of how major the intervention is and how likely it is to save, prolong, or improve one’s life or to alleviate suffering.

In facing these issues, the Roman Catholic Church has provided a guideline based on the distinction between ordinary and extraordinary care and has stated that there is a moral obligation to use ordinary means of preserving life. The Catholic Church defines extraordinary care as acts that, in a physician’s judgment, do not offer a reasonable hope of benefit or entail an excessive burden or impose excessive expense on the family or

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42 Kenneth Doka, Bruce Jennings, and Charles Corr, Ethical Dilemmas at the End-of-Life (Washington, DC: Hospice Foundation of America, 2005), 166.

community.\textsuperscript{44} I have observed in my ministry to patients that the concepts of futility and weighing the benefits versus burden are employed in the Adventist Health System hospitals instead of the ordinary/extraordinary dichotomy to assist people in making end-of-life decisions.

In dealing with end-of-life decisions, there are two extremes to avoid. The first is an attitude that one can end life, by an action, such as a lethal injection with the goal of bringing about a person's death. The second extreme mistakes the respect for the value of life with the erroneous belief that the life of a person on this earth has absolute value and all means must be taken for its preservation. This approach can lead to over-treatment, when a patient remains burdened by tubes and technologies even though it is evident that life cannot be extended. The Christian Medical and Dental Association, in their ethics statement on patient refusal of therapy, includes the claim that if “medical treatment only prolongs pain and suffering and postpones the moment of death, it may then be appropriate for a patient with decision-making capacity to refuse medical interventions.”\textsuperscript{45}

\textbf{Ethical and Philosophical Principles}

The ethical and philosophical principles of nonmaleficence, beneficence, autonomy, and justice are used widely in the health-care setting as a common foundation when making ethical judgments in end-of-life situations. Nonmaleficence is often


interpreted as "do no harm." The principle can more accurately be thought of as minimizing harm to as many interested parties as possible. Beneficence may be defined as that which requires the balance of goods that may result from a medical intervention against the harm. This principle states that patients should not feel obligated to accept medical interventions whose burdens outweigh the probable benefits.

The principle of justice states that special care should be taken to ensure that persons who are approaching the end of life are treated with respect for their dignity and without unfair discrimination. This is based on the theological principle that since all people are created in the image of God, their lives are equally significant. This practice the biblical writers term justice (Jer 22:15-16; 2 Cor 8:13-15). Justice means that care for the dying should be based on an individual's spiritual and medical needs and his/her expressed choices rather than on perceptions of one's social worthiness.

The principle of autonomy, a concept first introduced into modern ethical discussion by Emmanuel Kant, states that persons should not be forced to submit to a medical treatment that they find unacceptable. By autonomy he meant the faculty of the will to be its own lawgiver. It is a biblical principle that God created human beings with freedom of choice. God also asks them to use this freedom responsibly. People are free for example, to decide whether or not they want life-sustaining treatments when they are dying. It is not appropriate for others to force or withhold treatment. However, freedom in this sense does not mean that whatever treatment decisions people make are the right ones, simply because this is what the person desires. Thus a defensible biblical approach

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of autonomy, as it relates to end-of-life decisions, takes into consideration freedom of choice used responsibly, the sanctity of life, the sovereignty of God, and the stewardship required regarding our bodies and our resources.

Patient’s Willingness

How are the patient’s wishes to be determined? The answer depends on whether or not the patient has the mental capacity to express what he/she desires. When capacity is present, the medical team employs the standard of informed consent to identify a patient’s wishes. A patient has the right to be fully informed of the procedure and risks before consenting to any treatment. Informed consent requires discussion about risks, benefits, burdens, and alternatives.

Advance directives have the potential to be an excellent tool to determine the wishes of patients who are not mentally competent to express them. The most familiar form of an advance directive is the living will, a patient’s statement identifying the circumstances under which she or he does or does not want certain treatments. Many people including Christians have resisted the living will as ethically problematic because they believe that living wills are a step towards euthanasia.\(^47\) Another objection to living wills is the fact that people can never anticipate all future scenarios. Living wills can give permission to withhold or withdraw treatment under circumstances in which a person would actually want it.\(^48\)

A second form of advance directive has gained favor: a durable power of attorney.


\(^{48}\)Kilner, *Dignity and Dying*, 77.
This document legally enables an individual to indicate which person would be in the best position to make treatment decisions in accordance with the patient’s wishes if he or she is not able to express his/her wishes for treatment. The proxy decision-maker is to make certain that the wishes and values of the person are respected.

Love, an Approach to End-of-Life Care

A God-centered approach to end-of-life decisions is based on the biblical dimension of love. Paul calls love “the most excellent way” (1 Cor 12:31, NIV). Love to God and of neighbor involves self-sacrifice and, as Paul says in Phil 2:4 (NIV), “Each of you should look not only to your own interests, but also to the interests of others.” Jesus elaborates on the place of loving in the larger scheme of things. In Matt 22:34-40 Jesus, in response to a question as to which of all the commandments is the greatest, said that the first and the greatest is the command to love God. And the second is like it: “Love your neighbor as yourself.” He observed that these two commands together are the essence of what the Bible requires.

Kilner and Mitchell suggest that when dealing with bioethical issues, our first responsibility is to love God, which in ethical term means to follow a God-centered and reality bounded ethics that are practiced in accordance with how God has created and intended the world to be. Then within those bounds, our next responsibility is to love our neighbor as ourselves, which in ethical terms is the love-impelled ethics that seeks human well-being.49

Seventh-day Adventist Guidelines on Caring for the Dying

Seventh-day Adventists are concerned with the physical, emotional and spiritual care of the dying. The church, in its October 1992 Annual Council session, recommended a statement setting forth guidelines on the Care for the Dying. This document was approved by the General Conference of Seventh-day Adventist Executive Committee at the October 1992 Annual Council session. A summary of these biblically based principles are:

1. Human suffering has no expiatory or meritorious value.

2. Seventh-day Adventists do not practice “mercy killing” nor do they assist in suicide. They are opposed to active euthanasia, the intentional taking of the life of a suffering or dying person.

3. Allowing one to die by foregoing medical interventions that only prolong suffering and postpone the moment of death is morally different from killing.

4. Life-extending medical treatments may be omitted or stopped if they only add to the patient’s suffering or needlessly prolong the process of dying.

5. Relieve pain and suffering. When it is clear that medical intervention will not cure a patient, the primary goal of care should shift to relief from suffering.

6. Efforts to extend life have compassionate limits. Christians need not accept or offer all possible medical treatments that merely prolong the process of dying.

7. Tell patients the truth. Speak the truth with love (Eph 4:15). The truth should

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Seventh-day Adventist Church, “Guidelines on the Care for the Dying.”
not be withheld, but shared with Christian love and with sensitivity to the patient’s personal and cultural circumstances.

8. Respect personal choices. A person who is capable of deciding should determine whether to accept or reject life-extending medical interventions. Such persons should not be forced to submit to medical treatment that they find unacceptable.

9. Trust those closest to the patient. It is God’s plan for people to be nurtured within a family and a faith community. Decisions about human life are best made within the context of healthy family relationships, after considering medical advice.

10. Special care should be taken to ensure that dying persons are treated with respect for their dignity and without discrimination. Care for the dying should be based on their spiritual and medical needs and their expressed choices.

Summary

A Christian theology of death and dying is to be based upon a reflection of the meaning of our death in light of the death and resurrection of Jesus Christ. This theological reflection is not purely academic. It is a form of questioning based upon the confidence that God himself is the answer to the need for assurance that human life will survive death. A theological reflection of death and dying acknowledges the wonderful truth that death is a defeated enemy on one hand, but on the other, affirms that death continues as a physical event in the temporal lives of believers until the second coming of Jesus Christ.

Scripture does not support the intentional killing of another person for the relief of pain and suffering. The Bible portrays life as sacred because it is a gift from God and people reflect God’s image. This belief in the sanctity of life motivates Christians to
provide compassionate medical care, human companionship and spiritual support in order to alleviate pain and suffering of the dying.

A theological reflection on death and dying recognizes that preparation for death is an essential part of life for a Christian. A person who knows there is eternal life will approach end-of-life decisions differently from one who regards this present life as all there is. Advance planning for end-of-life care is understood to be an important part of good stewardship. Implementing an advanced planning document involves an in-depth discussion of the values and end-of-life wishes with family, friends, and physicians.
CHAPTER III

LITERATURE CONTRIBUTING TO AN UNDERSTANDING
OF ADVANCE PLANNING FOR END-OF-LIFE CARE

Introduction

Advance care planning is the process of planning for future medical care, particularly for the time when the patient is unable to make his or her own decisions. Effective advance directives are the outcome of good advance planning for end-of-life care. They were instituted in response to the realization that care toward the end-of-life is intended to reflect patient wishes.

Despite the institutionalization of advance directives in state and federal law and widespread public support for advance care planning, the evidence indicates that implementation of advance directives is low, especially among the minority and ethnic populations. A review of the literature suggests that between 18 percent and 30 percent of Americans have completed an advance directive.\(^1\) The completion of advance directives is even lower among Hispanics who are about one-third as likely as non-Hispanic whites to have living wills.\(^2\)

Dr. Maria Silveira and colleagues found support for the continued use of advance

\(^1\)Wilkinson, Wenger, and Shugamman, Literature Review on Advance Directives, 14.


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directives in a study published in April 2010. They used data from survey proxies in the Health and Retirement Study involving adults sixty years of age or older who had died between 2000 and 2006. The researchers found that 42.5 percent of patients had faced treatment decisions near the end of their lives, of which 70.3 percent lacked the ability to make choices because of their mental or physical health. Among the group, 67.6 percent had advance directives. According to the study, patients who had prepared advance directives received care that was strongly associated with their preferences.³

**Factors That Influence the Completion of Advance Directives**

Carol White conducted interviews with thirteen senior citizens to determine how they felt about life and death and which factors influenced their decision-making about advance directives. She found that the process of deciding whether to implement advanced directives is multifaceted, complex, and involves one’s values, age, time, stress, health status, knowledge, concern for others, and quality of life.⁴

In the setting of a rural office practice, Marchand, Cloutier, Gjerde, and Haqu interviewed ten patients over sixty years of age to explore what influences the completion of advance directives. They found that an understanding of the advance directives documents and their purpose constituted the major difference between people who do and do not complete advanced directives.⁵

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G. A. Sach found in his study described in the Hastings Center Report that people who do execute advance directives tend to be older, white, well-educated persons who plan for the future.\(^6\) A similar study by Nishimura et al. affirmed that completion of advance directives was associated with higher levels of education. Ninety-three percent of the patients who completed advance directives were at least high school graduates. Compared with less-educated patients, those with at least a high school education found advance directives forms easier to read and understand. According to their study, the language of preprinted advance directives forms is at the 11th or 12th grade reading level.\(^7\) Rosnick and Reynolds analyzed data of 451 adults and found the following factors most consistently indicated which adults had executed advance directives: (1) increasing age, (2) higher income, and (3) higher quality of life and with more control.\(^8\)

Donna Helen Crisp, over a period of four months, interviewed eight healthy older adults in an attempt to understand the process they underwent in their decision to obtain and execute advance directives. She found that the influence of family had the greatest impact on the choice to execute an advance directive. One significant marker is the personal experiences with dying loved ones. Another important aspect was the concern to ease the burden on their families with regard to end-of-life decision-making on their behalf.\(^9\)

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A qualitative study by Moore and Sherman sought to understand the meaning of end-of-life decision-making for nine minority and eleven white, low-income community-dwelling seniors. They found that three concerns lay behind the decision of these seniors to execute advance directives: (1) they did not want to be put on machines, (2) they did not want to be a burden to their families, and (3) they did not want their lives prolonged by expensive medical treatments.\(^9\)\(^10\)

**Importance of Advance Directives**

Modern medical technology has the ability to supply the technology to prolong life, but often there is a lack of preparation or documentation of the patient and family wishes on when and for how long to administer this care. A study of 864 critical care nurses indicates that family lack of understanding about life-saving measures is a prominent barrier in providing end-of-life care.\(^11\) A study of forty-four nurses concluded that nurses' greatest frustration with end-of-life transitions was having to deal with the complex emotions and indecisiveness of patients' families.\(^12\) Another survey found most family caregivers involved in a recent decision to withdraw or withhold life support from a relative reported feelings of uncertainty, guilt, regret, and anger.\(^13\)

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Peter Ditto, Nikki Hawkings, and David Pizarro challenge the assumption that people can accurately predict their future preferences for life-sustaining medical treatment. Their research suggests that people will often fail in their attempt to predict their future wishes because (1) they have inaccurate beliefs about life-sustaining medical treatments, (2) they fail to appreciate how their current physical and emotional state affects their predictions about future states, (3) they under-appreciate how well they will cope with serious illness, and (4) they weigh certain aspects of information differently when making decisions about the immediate and more distant future.\(^{14}\)

**Obstacles for the Completion of Advance Directives**

Wilkinson, Wenger, and Shugarman, in a review of literature related to end-of-life directives, concluded that the following obstacles are the most likely to impede the completion of advance directives: (1) inadequate knowledge about advance directives and how to complete the form, (2) perception that advance directives are difficult to execute, (3) perception that even if completed clinicians will not follow advance directive statements, (4) reluctance to broach the issue of death and end-of-life-planning, (5) view that advance directives are unnecessary because one’s family or provider will know what to do, and (6) perception that advance directives are important for others, but not for themselves.\(^{15}\)


Henry Perkins identifies three problems with the implementation of advance directives. The first is inaccessibility by health-care providers. Too few signers routinely carry their advance directive with them; or, in a crisis, fail to distribute their directives to all possible decision makers. When unable to access advance directives in emergency situations, health personnel, when faced with life-or-death decisions, often have only a bystander’s recollection of a patient’s wishes.

The second problem is the poor proxy representation. A proxy is an individual who is designated by a legal document known as a power of attorney to make health-care decisions on behalf of another person who is unable to make or communicate health-care decisions. Many proxies lack the knowledge, insight, or courage to fulfill their role, or they may not be aware of the patient’s desires.

The third problem is physician non-adherence. Most physician non-adherence to advance directives stems from miscommunication or misunderstanding about a patient’s wishes. 16

Barriers to physician initiated advance directives discussions include reluctance to discuss these matters with the patients and the patient’s family. Physicians are themselves often uncomfortable to discuss how to handle end-of-life issues or they may lack familiarity with suitable alternatives to aggressive treatment. The physician’s lack of time for these discussions is one factor that cannot be over-looked; nor can one ignore the perception among some physicians that patients and families do not want to talk about end-of-life issues. The families, it is believed, do not wish to discuss palliative care,

hospice or other matters associated with the death of their loved one. Therefore, for these and other reasons, some physicians conclude that advance directives discussions are not needed.\textsuperscript{17}

**Issues Affecting End-of-Life Care and Completion of Advance Directives Among Latinos**

Advance directives have not been uniformly implemented by various segments of the United States population. Studies have consistently shown a lower baseline prevalence of advance directive completion for Hispanics compared with non-Hispanics. Degenholtz et al. in their study concluded that Hispanics are about one-third as likely as Caucasians to have living wills.\textsuperscript{18} Cultural differences among those from non-Caucasians backgrounds can help explain the reluctance of these groups to implement end-of-life decisions. According to Caralis et al., 32 percent of the Latinos and 22 percent of Caucasians did not want to name a proxy on an advance directive. Latinos wanted life-prolonging treatment to continue regardless of how ill they were. However, when asked about end-of-life actions should they be in a vegetative state, Latinos did not want any intervention.\textsuperscript{19}

Studies show that discomfort with advance care planning is particularly strong within the Hispanic community as compared with the Caucasian population. Murphy et al. noted in their study that Mexican Americans did not want physicians to discuss death


\textsuperscript{18}Degenholtz et al., "Persistence of Racial Disparities in Advance Care Plan Documents among Nursing Home Residents," 378.

and dying because doing so might be harmful to the patient. In Morrison et al. the findings among Puerto Rican subjects are similar to those of Murphy et al. regarding physician’s involvement in discussing death and dying.

Among Hispanics the lack of acceptance of advance directives may stem from a view of collective family responsibility. Latino patients may be reluctant to formally appoint a specific family member to be in charge because of concerns about offending other relatives. The common Hispanic phenomena of present-time orientation (presentismo) may also contribute to lack of advance planning among Latinos.

In the United States health-care system, the value of autonomous decision-making is strongly held; however, the Hispanic population seems to value more a collective model of decision-making. According to Newman et al., the concept of jerarquismo (respect for hierarchy) and personalismo (trust borne of mutual respect) anticipates the tendency of some Hispanic patients to defer to their families or to a physician the decisions in regard to end-of-life issues. Morrison and Meier found in their study that Hispanics were more likely to value collective decision-making rather than individual decision-making and to worry that they would not be treated as well as others or that

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24Ibid., 5.
physicians might prematurely discontinue life-support if they made decisions for less aggressive care.25

J. Kwak and W. Haley reviewed thirty-three empirical studies investigating racial/ethnic variation in end-of-life decision-making and found that Hispanics were more likely to desire family-centered decision-making as compared to the Caucasian population. Hispanics, as a group, were more concerned that life-sustaining treatments would be withdrawn prematurely.26

Searight and Gafford identified in their research that Hispanics (1) prefer to avoid the emotional and physical stress caused by addressing end-of-life issues, (2) family members actively protected the terminally ill from knowledge of their condition, (3) in terms of decision-making, Mexican Americans appear more likely to consider family members, rather than the patient alone, as holding the decision making-power regarding life-support.27

The Perkins et al. study indicates that Mexican-Americans believed that the health-care system controls treatment but serves patients well, wanted no futile life support, had not heard about advance directives before but believed they can help staff know or implement a patient’s wishes, realized the influence of family in terminal care situations but had not told anyone their wishes.28


Table 1 illustrates some issues that may affect end-of-life care and the Latino decision-making process.29

**Interventions to Increase Advance Care Planning**

A main concern of advance care planning is whether discussion about end-of-life care and advance directives would have a negative impact on patients. The evidence

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suggests that advance care planning is not distressing to patients and that intensive educational interventions are acceptable to patients, families, and physicians. The literature review suggests that repeated discussions of patient preferences as well as accessible documentation of these preferences are necessary to ensure that care is consistent with the patient’s current situation and wishes.  

B. Guo and C. Harstall conducted a systematic review of the literature on advance directives consumer education intervention publications and the effect these publications had on those who utilized them. They found that more comprehensive interventions (an education session plus telephone reminder or an active seminar) yielded higher advance directives completion rates of 30-40 percent in comparison to those who utilized simple interventions (written materials alone, material with educational videotapes, and physician-initiated discussions).  

Stephen Hines et al. found that conversations between patients and their surrogates were associated with the surrogates believing they had a better understanding of the patient’s wishes. Surrogates wanted written and oral instructions more often than patients wanted to provide them and knowing the patient’s wish to stop treatment in the present situation was more important to most surrogates than the physician’s recommendation to stop treatment.  

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Spiritual Needs at the End-of-Life Care

People nearing the end-of-life may have spiritual needs as compelling as their physical concern. Spiritual needs may involve finding meaning in one’s life and, when possible, ending disagreements with others. To satisfy this need, the dying person might find peace by resolving unsettled issues with friends or family. Many Latinos, like others in the general population, find solace in their faith. Praying, talking with someone from one’s religious community, reading religious texts, or listening to religious music may bring comfort and assurance.

In one qualitative study, terminal patients were asked to identify spiritual needs at the end-of-life. Their spiritual needs clustered around the following themes: a need for religion, companionship, involvement, control, finishing business, and having a positive outlook.33 Michael Yedidia and Betsy McGregor interviewed thirty patients in their last months of life to identify themes describing the patient’s perspective on death. Seven motifs were identified: struggle (living and dying is a struggle), dissonance (dying is not living), endurance (triumph of inner strength), incorporation (belief system accommodates death), coping (working to find a new balance), and quest (seeking meaning in dying). The authors concluded that the overall theme of quest or seeking meaning in dying fit the definition of meaning and purpose associated with spirituality.34

Anthony Greisinger and colleagues conducted a study using open-ended interviews to develop items of concern to terminally ill cancer patients. Patients and their


families were asked to rank the importance of each item on a five point Likert scale.\textsuperscript{35} Existential concerns, spiritual concerns, and family concerns emerged as the main categories to patients and their families at the end-of-life. Existential concerns included having a sense of hope, knowing that one’s life has meaning and purpose, and knowing that one’s life has been productive. Spiritual concerns included finding strength in one’s beliefs and finding comfort in one’s faith. Family concerns, which could be included in the realm of spirituality as connectedness, included knowing that one’s family appreciates one, being able to say goodbye, expressing feelings to family, and knowing family will be alright without them. Patients and their families rated hope as the highest of all the factors.\textsuperscript{36}

A 1997 Gallup survey “Spiritual Beliefs and the Dying Process” reported that 54 percent of the respondents said that if they were dying they would want human contact, especially someone with whom they could share their fears and concerns. Forty-seven percent expressed their desire for holding hands or touch. Fifty percent indicated that prayer would be very important during their dying process.\textsuperscript{37} These practices lie within the broader domain of spirituality.

It is important that the church play the role of a Community of Care in its response to death and dying issues. K. L. Braun and A. Zir interviewed 121 clergy and

\textsuperscript{35}The Likert Scale is an ordered, one-dimensional scale from which respondents choose one option that best aligns with their view.


congregants affiliated with Christian churches in Honolulu, Hawaii. Participants identified the following roles for the church in end-of-life care: (1) to help congregants prepare for death, both spiritually and practically; (2) to facilitate resolution of conflict and forgiveness; (3) to clarify if or how church theology should guide attitudes and practices related to death and dying; (4) to administer the appropriate rituals; and (5) to provide outreach to sick, dying, and bereaved members.  

Summary

Advance care planning for end-of-life care is a multifaceted and complex process that involves the person’s values, faith, spiritual needs, knowledge, and concern for others. The literature review above indicates that comprehensive educational interventions that include educational booklets and an active seminar yielded higher completion rates than those interventions that aimed only for completion of advance directives. According to the literature survey for this project the influence of family and the concern to ease the burden of the family with regard to future end-of-life decision-making have the greatest impact on the choice to complete an advance directive.

These findings affirm that interventions for advance care planning for end-of-life care should take into consideration the cultural and ethnic background of the targeted group. The process designed for this project acknowledges the above findings and includes them as part of a seminar that will assist Hispanic families to prepare and implement advance planning for their end-of-life care. The seminar is targeted to competent adult members of El Divino Salvador Presbyterian Church and Monrovia.

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Seventh-day Adventist Spanish Church in Los Angeles, California. The participants are sixty years or older who are able to understand the nature, extent and probable consequences of their health-care decisions. The literature review for this project demonstrates that (1) Hispanics are about one-third as likely as Caucasians to have completed an advance directive, (2) family is highly valued among Latinos, and (3) the extended family is likely to be involved in the process of decision-making.
CHAPTER IV

LOVING CONVERSATIONS: A SEMINAR TO ASSIST HISPANIC FAMILIES TO IMPLEMENT ADVANCE PLANNING FOR THEIR END-OF-LIFE CARE

Introduction

Advance care planning is the process that enables a person, in collaboration with loved ones and clinicians, to make future health-care decisions should the person be unable to communicate his/her wishes.

Advance care directives are written health-care instructions that are developed to provide a practical process for ensuring patient autonomy at the end-of-life. Dr. Henry Perkins states that “advance directives remind physicians to value patients as partners in planning care. Advance directives also encourage planning for death. Many people do not deny death so much as ignore it. Advanced directives act as concrete aids in prodding people to overcome their aversions and to face the hard decisions about dying.”

Health decisions made before they are needed is truly a gift to the family. Apart from the emotions associated with sudden illness, discussions about the preferences for treatment, in a more relaxed an intentional setting, enables the family to have a clear understanding of their loved one’s wishes, and takes the burden of decision-making off the family and others. The seminar described below is designed to encourage family

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conversations on advance care planning for end-of-life decisions within the context of Christian stewardship and personal interaction.

**Objectives of the Seminar**

By the end of the seminar, the participants will be able to:

1. Apply Christian principles to their end-of-life care.

2. Understand and complete an agent for health-care advance directive.

3. Use tools to engage in meaningful conversations with families about end-of-life issues and wishes.

**Content and Resources**

The seminar is targeted to competent adult members of El Divino Salvador Presbyterian Church and Monrovia Seventh-day Adventist Spanish Church, sixty years or older, who are able to understand the nature, extent, and probable consequences of their health-care decisions. Subjects who fit this description are invited to a meeting where they will participate in the seminar and complete the informed consent form and the pretest survey.

The seminar consists of three one-hour sessions. The first session focuses on advance planning for end-of-life care as part of Christian stewardship. This session includes biblical and theological principles associated with death and dying.

The second session deals with how to have caring conversations with the family about end-of-life issues. It includes: definitions of medical terms associated with end-of-life care, a worksheet to identify an individual's wishes for medical treatment, spiritual and emotional support for end-of-life care, and tools to engage in meaningful
conversations with family members about end-of-life issues and wishes.

The agent for health-care is invited to join the participants for the last meeting. This session provides opportunity for sharing and feedback and to evaluate the seminar. Each participant is asked to complete a post-test questionnaire designed to provide quantitative data to draw conclusions and to make recommendations for further implementations.

**Conceptual Framework**

A Christian Perspective of End-of-Life

The participants of the seminar will be able to apply Christian principles to planning their end-of-life care. These principles are based on the ethical and biblical guidelines prepared by the Seventh-day Adventist church in the document "On the Care for the Dying" and the Christian view of end-of-life that acknowledges the inherent negativity of death on one hand, but on the other, affirms the reality of a future beyond death based upon the death and resurrection of Jesus Christ.

A Christian’s perspective of end-of-life decisions takes into consideration that the most important thing an individual can do to prepare for the dying process is to become personally acquainted with Jesus and accept him as his/her personal Savior. A good death from this perspective is peaceful because the dying person has the assurance of eternal life.

The core of a Christian view of the end-of-life is the principle that life is a precious gift and we are responsible to be good stewards of this gift. This stewardship includes care for our bodies, our health, and our resources. In the same way, we are responsible to God for our life-style and health care choices. Expressing our wishes
regarding end-of-life situations is part of this stewardship.

Advance Directives Premises

Advance directives are an important element of advance planning for end-of-life care because they identify preferences for life-sustaining care and provide a framework for decision-making at the end-of-life. This seminar is based on the following advance directive premises: (1) The belief that planning for the future will effectively influence future events; (2) a willingness to engage in discussions that some may perceive as uncomfortable and difficult, such as imagining a situation in which one is seriously ill and; (3) a presumption that one or at most two individuals will speak for the incapacitated person.2

Family Influence

The literature review for this project indicates that the influence of family had the greatest impact on the choice to execute advance directives. This decision is driven by the concern people have to ease the burden on the families with regard to end-of-life decision-making.3

The Stages of Change Model is used widely in health behavior interventions and assumes that behavioral change is associated with cognitive decision rules and principles. According to this model, as people move toward adopting new behaviors, they shift towards the positive, rather than negative consequences.4 Louis J. Medvene et al. applied

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2Morrison and Meier, “High Rates of Advance Care Planning,” 2421-2426.

3Crisp, “Healthy Older Adults Execution of Advance Directives,” 185.

the above principle of the Stages of Change Model to people signing advance directives. The authors make the point that people shift from the negative belief that discussing advance directives with the family would make them uncomfortable to the positive belief that by signing an advance directive, the person will relieve the family from having to make difficult medical decisions on his/her behalf without knowing his/her wishes.5

The seminar recognizes the high value Hispanics place upon family and will therefore emphasize the benefits that can be expected when families engage in meaningful conversations about end-of-life issues and sign an advance directive.

Program Evaluation

The purpose of this project was to develop and evaluate the responses to a seminar to encourage Hispanic families to have conversations on advance planning for end-of-life care. The majority of participants thought that the overall effectiveness of the seminar was excellent or good. The seminar was effective in achieving 100 percent participation among the subjects in expressing their end-of-life wishes to their family. A key motivator, expressed by the participants of the seminar, was to relieve their loved ones from having to make difficult decisions on their behalf without knowing their end-of-life care wishes.

Advance planning on end-of-life care is a process people can use to prepare themselves and their loved ones for dying. An important aspect in preparing for the dying process is to be a responsible steward of one's health-care choices. The majority of the

seminar participants agreed with the statement that planning for end-of-life care is part of being a good steward. Within the context of this seminar, stewardship for advance care planning involves the application of biblical principles to all decisions relating to end-of-life matters.

Advance directives are an important element of advance care planning. They are written statements which convey a person’s wishes to his or her family and the medical team in the event that person becomes unable to discuss such matters. The intervention showed an increase of 20 percent in the completion rates of power of attorney for healthcare and in living will advance directives documents.

However, a higher percentage of participants (60 percent) signed a power of attorney for health-care than the living will advance directive document (40 percent). This data reflects the principle introduced in the seminar that conversations with family members should result in assigning at least one individual as the agent for health-care and making sure that this person understands and agrees to abide by individual’s preference for end-of-life care.

Summary

The Loving Conversation Seminar was designed to encourage family conversations on advance care planning for end-of-life care. The seminar consists of three one-hour session. The first session focuses on advance planning for end-of-life as part of Christian stewardship. The second session deals with how to have caring conversations with the family about end-of-life issues. The last session provides opportunity for sharing and feedback.
The workbook designed for this project is based on the following conceptual framework.

1. The most important thing a person can do for advance care planning is to become personally acquainted with Jesus as one’s personal Savior.

2. Christian principles can be applied to end-of-life care planning.

3. Expressing one’s wishes regarding end-of-life situation is good stewardship.


5. Discussing end-of-life wishes with the family will relieve their loved ones from having to make difficult decisions on their behalf without knowing their end-of-life care wishes.

The seminar was effective in achieving 100 percent participation among the subjects in expressing their end-of-life wishes to their loved ones. There was an increase of 20 percent in the completion rates of power of attorney for health-care and in living will advance directives documents.
CHAPTER V

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Introduction

The purpose of this project was to develop and evaluate the response to the Loving Conversation seminar at El Divino Salvador Presbyterian Church and Monrovia Seventh-day Adventist Spanish Church. The seminar was designed to assist Hispanic families to have meaningful conversations with their loved ones on practical preparations for advance care planning for their end-of-life decisions within the context of Christian stewardship. The seminar was conducted at the Monrovia Seventh-day Adventist Church in December 2009 and at the El Divino Salvador Presbyterian Church in February of 2010. The seminar consisted of three one-hour sessions and was targeted to members of the churches mentioned above who were sixty years of age or older.

El Divino Salvador church is a Spanish-speaking congregation located in East Los Angeles, California. According to senior pastor Eliseo Morales, the congregation has a membership of ninety members; 15 percent are older than sixty years of age.

The Monrovia Spanish church is located in the city of Monrovia, California. According to associate pastor Luis Villamizar, the Monrovia church has a membership of 110; 10 percent are older than sixty years of age.

Subjects who fitted the target audience of sixty years or older were invited to participate in the seminar. There were six participants from the El Divino Salvador and
four from the Monrovia Spanish Church. After obtaining informed consent, participants completed the pre-test instrument. The post-test survey was administered at the last session of the seminar.

Summary of Findings

Participant Demographics

Table 2 provides information of the participant demographics. The sample included five men and five women. Eighty percent of the participants were married and twenty percent stated that they were single. Sixty percent were sixty to seventy years old and 40 percent were older than seventy-one years of age.

Table 2. Participants Demographics

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-65</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td>66-70</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>71-75</td>
<td>2</td>
<td>20</td>
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<td>81+</td>
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<td>50</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>50</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>8</td>
<td>80</td>
</tr>
<tr>
<td>Single</td>
<td>2</td>
<td>20</td>
</tr>
</tbody>
</table>
Planning for End-of-Life Care Is Part of Good Stewardship

The core of the Christian view presented in this seminar is that life is a precious gift and believers are responsible to be good stewards of this gift. Christians are responsible to God for their life-style and health-care choices. Expressing the wishes regarding end-of-life situations is a vital part of Christian stewardship.

Table 3 shows the participants perception on this issue. The comparison of the pre-test data with the post-test shows that the intervention provided for this project did not shift significantly the participant’s perceptions. Eighty percent of the participants agreed that planning for end-of-life care is part of being a good steward, 10 percent disagreed with the statement, and 10 percent were not sure.

Table 3. Planning for end-of-life as part of stewardship

<table>
<thead>
<tr>
<th>Plan for end-of-life care is part of being a good steward</th>
<th>Pre-test N</th>
<th>Percent</th>
<th>Post-test N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>1</td>
<td>10</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Disagree</td>
<td></td>
<td></td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Not sure</td>
<td>1</td>
<td>10</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Agree</td>
<td>3</td>
<td>30</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>5</td>
<td>50</td>
<td>5</td>
<td>50</td>
</tr>
</tbody>
</table>
Family Influence

The literature review for this project indicated that among Hispanics, the influence of family has a great impact on end-of-life care decisions. The seminar emphasized the positive concept that by entering into meaningful conversations with their families about their end-of-life care the participants relieve their loved ones from having to make difficult decisions on their behalf without knowing their wishes.

The last session of the seminar provided a time for sharing and feedback. During this session most of the participants expressed their concern that their dying would cause their loved ones to experience a significant emotional burden. They stated how important it is to have meaningful conversations with their family about their end-of-life wishes so that their loved ones will find it easier to cope with future end-of-life decisions made on their behalf.

Table 4 shows the response of the participants to the question “I would like to have someone I trust to make health-care decisions for me.” Eighty percent agreed with the statement before the implementation of the seminary compared to 90 percent post intervention. As a result of the intervention, 100 percent of the participants expressed their end-of-life wishes to their loved ones. This reflected an increase of 50 percent in comparison with the pre-test data. However, when asked, “How was your family response to your conversation about your end-of-life wishes?” 40 percent of the participants said it was fair and another 40 percent reported it as good. This response is consistent with the literature review that showed that Hispanics prefer to avoid the emotional and physical stress caused by addressing end-of-life issues.
Table 4. Conversations on end-of-life wishes with family

<table>
<thead>
<tr>
<th></th>
<th>Pre-test</th>
<th>Percent</th>
<th>Post-test</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would like someone I trust</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>make health-care decisions for me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td></td>
<td></td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Not sure</td>
<td>2</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>5</td>
<td>50</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>3</td>
<td>30</td>
<td>6</td>
<td>60</td>
</tr>
<tr>
<td>I have expressed my end-of-life wishes to my loved ones</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5</td>
<td>50</td>
<td>10</td>
<td>100</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don’t know</td>
<td>1</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How was your family response?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very poor</td>
<td></td>
<td></td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Poor</td>
<td></td>
<td></td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Fair</td>
<td>4</td>
<td>40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>4</td>
<td>40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>1</td>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Advance Directives

Advance directives are an important part of advance planning for end-of-life care because they identify preferences for life-sustaining care and provide a framework for
decision-making at the end-of-life. There are two types of advance directives in California, the living will and the power of attorney for health-care. In the living will, the person lists instructions about future medical treatments. In the power of attorney for health-care, the person designates another person for making future health-care decisions.

Before the seminar, 40 percent of the participants reported that they had signed a health-care power of attorney and only 20 percent expressed that they had signed a living will advance directive document. Table 5 shows an increase of 20 percent in the completion rates of power of attorney for health-care and living will advance directives documents among the participants after the intervention provided for this project.

**Table 5. Advance directives completion**

<table>
<thead>
<tr>
<th></th>
<th>Pre-Test</th>
<th>Percent</th>
<th>Post-Test</th>
<th>Percent</th>
<th>Percent Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td></td>
<td>N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have signed a power of attorney for health-care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
<td>40</td>
<td>6</td>
<td>60</td>
<td>20</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>50</td>
<td>4</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>I don’t know</td>
<td>1</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have signed a living will</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
<td>20</td>
<td>4</td>
<td>40</td>
<td>20</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>40</td>
<td>6</td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>I don’t know</td>
<td>4</td>
<td>40</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The persons chosen by the participants as agents for their power of attorney for health-care were invited to attend the last meeting of the seminar. Two agents attended the meeting. They were husband and wife who had designated each other as their agents. According to the other participants of the seminar who signed a power of attorney for health-care, their agents were not able to attend the meeting because of previous commitments.

Overall Effectiveness of the Seminar

The post-test section that dealt with the seminar evaluation included one item where the participants were asked to evaluate the overall effectiveness of the seminar and to answer the following open questions: (1) I am glad that I came to this seminar because . . ., (2) I am not sure I am glad I came this seminar because . . ., and (3) what suggestions do you have for improvement of future seminars?

Table 6 shows the post-test data that evaluated the overall effectiveness of the seminar as follows: 56 percent of the participants rated the seminar excellent and 33 percent said it was good. Only 11 percent of the participants said the effectiveness was fair. One of the participants did not respond.

The participants made the following comments in the post-test survey in relation to the effectiveness of the seminar: (1) "I really enjoyed the seminar," (2) "I now feel more prepared to face end-of-life decisions," (3) "I have learned a lot about the death process. I will put into practice what I learned in this seminar with my loved ones," (4) "It has been a very good seminar. I am very satisfied. Thanks to the pastor for his time in teaching us about this important topic."
Table 6. Effectiveness of the seminar

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall effectiveness of the seminar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very poor</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Poor</td>
<td>3</td>
<td>33</td>
</tr>
<tr>
<td>Fair</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Good</td>
<td>3</td>
<td>33</td>
</tr>
<tr>
<td>Excellent</td>
<td>5</td>
<td>56</td>
</tr>
</tbody>
</table>

The participants provided the following three suggestions to improve future seminars: (1) “Continue teaching this seminar,” (2) “show some visual illustrations about artificial-life support system,” (3) “offer the seminar on another day. This may improve attendance.”

Conclusions

From a Christian perspective, advance care planning for end-of-life care is broader than planning for future medical care alone, particularly for the time when a person may be unable to make his or her own decisions. Advance care planning is a complex process that involves the person’s values, faith, spiritual needs, knowledge, and concern for others.

The Christian view on advance care planning acknowledges the inherent negativity of death on one hand, but on the other, affirms the reality of a future beyond death based upon the death and resurrection of Jesus Christ. From a Christian’s perspective, the most important thing a person can do on the issue of advance care
planning is to accept Jesus as his/her personal Savior. To know Jesus as one’s personal Savior brings peace and the assurance of eternal life.

**Recommendations**

The following are recommended for implementation in future seminars with the hope that they will encourage church members to engage in advance care planning for end-of-life decisions:

The church should play the role of a Community of Care in its response to death and dying issues. Seminars, such as the intervention used in this project, can play an important role in helping church members to prepare for death and to provide practical Christian principles to assist a person to act upon matters related to death and dying.

Do not limit the target audience to members sixty years of older. A younger audience will benefit from the principles introduced in the seminar. One of the participants brought her sixteen years old granddaughter to the first session. After the first meeting, this young lady raised some ethical and theological issues related to end-of-life care. The seminar can provide a golden opportunity to engage the younger generation with their parents or grandparents to converse about the importance of preparing for end-of-life care decisions.

Promote the utilization of power of attorney for health-care advance directive documents. Conversations with family members should result in assigning one individual as the health-care agent and making sure that this person understands his/her loved one’s spiritual, emotional, and medical preferences for end-of-life care.

Invite a medical doctor or other health-care professional to be present for the session that deals with medical terms related to end-of-life care. There were some health-
care related questions raised by the participants that the facilitator of the seminar was not able to answer. Participants suggested the use of visual illustration when presenting the artificial life support system topic.

One of the participants made the suggestion that in order to improve the attendance of the participants and agents for health-care, who are invited to join the participants for the last meeting, the seminar should be part of a regular church service. The seminar could be presented on a couple of Sabbaths. The first session could be developed as part of a sermon series to introduce Christian principles in planning for end-of-life care. The last two sessions could be held on Sabbath afternoons.

The most important element for advance care planning is for the participants to become acquainted with Jesus as his/her personal Savior. This brings about peace and the assurance of eternal life as well as the motivation to fill the believer's numbered days on this earth with work for the kingdom of God.
Session One: Biblical and Theological Principles on Advance Planning for End-of-Life Decisions

“For everything there is a season and a time - for every matter under heaven: A time to be born and a time to die” (Ecclesiastes 3:1-2).

Introduction

With the capacity of medicine to prolong life through modern technology, dying people, who are mentally competent to make health care decisions, may find themselves in situations where they have to decide whether to receive or refuse medical treatment to prolong their lives and thus postpone the moment of death. Sadly, people do not always have the mental capacity to make medical treatment decisions when they must be made. For example, when patients are unconscious or confused, they are unable to state the level of medical intervention they want. Since decisions even then should be in accordance with the patient’s wishes, the key issue becomes whether or not the person has expressed those wishes in advance.

We plan in advance for all kinds of events such as birthday parties, anniversary celebrations and vacations. In spite of the fact that planning in advance is something we do everyday, we often don’t plan in advance for one of the most important decisions we can make: our health-care. Advance planning for future health-care choices is a wise and responsible decision. Advanced planning provides opportunity to think about the kind of health-care you want if you ever became too sick to communicate your wishes.
Discussions with your family and others who are close to you so that they understand and accept your decisions are important.

Making decisions about future medical care and sharing your wishes with your loved ones is truly a gift to your family. Talking about your preferences for treatment will save your family the heartache of having to make decisions for you without knowing your wishes. It will make a difficult time more manageable and your family will feel reassured that they respect or honor your wishes.

**Purpose**

The purpose of the seminar is to encourage family conversations on advance care planning for end-of-life decisions within the context of Christian stewardship. By the end of the seminar, you will be able to:

1. Apply Christian Principles to your end-of-life care.
2. Understand and complete an agent for health-care advance directive.
3. Use tools to engage in meaningful conversations with your family and others about end-of-life issues.

**Death Is a Defeated Enemy**

More than two million people die in the United States each year. At the end-of-life, each story is different. Death may come suddenly, or a person may linger, gradually failing until death comes. For some older people, the body weakens while the mind stays alert. Others remain physically strong, and cognitive losses take a huge toll. But for everyone death is inevitable. Unless Christ returns soon, death will come to each one of us. The Christian message assures us that this mysterious enemy called death was
conquered when Jesus died on the cross and rose to life again. His promise is that all who trust in him are assured of their own resurrection from death.

Paul's teaching is that "the Lord himself will come down from heaven, with a loud command, with the voice of the archangel and with the trumpet call of God and the dead in Christ will rise first. After that, we who are still alive and are left will be caught up together with them in the clouds to meet the Lord in the air. And so we will be with the Lord forever" (1 Thess 4:16, 17, NIV). Believers have the assurance that death will not have the last word. God will resurrect humans to a new life just as he resurrected Jesus.

**Good Death**

Some people think of the ideal death as going to bed one night and simply not wake up. Most of us would probably define a "good death" as dying peacefully, possibly aware that we are near our end, having achieved most of what we wished to achieve in our lives. Dr. Jon Dunlop, a Christian physician, offers his definition of a good death:

1. A good death is the natural trajectory of faith commitments made earlier in life. There should be no discontinuity between the faith we live by and the faith we die by. A believer finds ultimate value not in this life but in an eternal relationship with God.

2. A good death may require advance planning. This involves an in depth discussion of the values and wishes with the family and the person appointed as the Health Care Agent. Advance directives should be consistent with Christian values and faith.

3. A good death has completed relationships including those that need reconciliation. There are four things that need to be said as life comes to an end: I love
you; I thank you; I forgive you; and forgive me. These four statements may provide an occasion to reconcile relationships that have been broken.

4. A good death comes after we cease clinging to the things and values of this world and increasingly embrace eternity.

5. A good death is peaceful, for the dying person knows that it will lead to resurrection and eternal life in God’s presence.

Stewardship at the End-of-Life

Stewardship is about being a faithful disciple, caring for and managing all that God has given us in all the stages of life. Christian stewardship is about making choices and how our choices affect us and others. As Christians, we believe that life is a precious gift and as stewards of this gift we are responsible to care for our bodies, health and resources. Therefore, as believers we are responsible to God for our life-style and health-care choices. From this perspective, stewardship at the end-of-life involves applying biblical principles to advance care planning. We understand that it is important that we express our wishes regarding end-of-life situations and that this choice is part of stewardship.

The following guidelines may help you and your family to have a meaningful conversation about planning for your end-of-life care:

1. The truth should not be withheld but shared with Christian love and with sensitivity to the patient's personal and cultural circumstances (Eph 4:15).

2. Treat the dying persons with respect and dignity.

3. Human suffering has no expiatory or meritorious value.
4. A person who is capable of deciding should determine whether to accept or reject life-extending medical interventions. Such persons should not be forced to submit to medical treatment that they find unacceptable.

5. Christians generally rejects euthanasia the intentional taking of the life of a suffering or dying person.

6. Allowing death to come to a person by foregoing medical interventions that only prolong suffering and postpone the moment of death is morally different from killing.

7. Christians need not accept or offer all possible medical treatments that merely prolong the process of dying. When it is clear that medical intervention will not cure a patient, the primary goal of care should shift to relieve from suffering.

8. Life extending medical treatments may be omitted or stopped if they needlessly prolong the process of dying.

Thinking about Your End-of-Life Care

The following questions are intended to help you think, make decisions and communicate your end-of-life care wishes to your loved ones and people involved with your care. You may skip any question you are not ready to answer or that makes you feel uncomfortable.

1. If you were to die today, would you have the assurance of eternal life in Christ Jesus?

2. If you could plan the circumstances when you are close to death, what would you choose? Give a brief answer to the following:

   a. Persons with you at your death:
b. Location and Surroundings:

c. What are your fears regarding the end of your life?

d. How do you want to be remembered?

**Agent for Health-Care**

Let’s say you are no longer able to make your own health-care decisions and that someone else will have to decide what is best for you. In legal terms in California this person is called “an attorney-in-fact”, or an “agent for health-care.” The person(s) you choose should be at least 18 years or older. The best people to make decisions for you are people to whom you trust and communicate well with.

Things to consider when selecting your agent for health-care are:

1. The person is willing to speak on your behalf.
   
   ( ) Yes  ( ) No  ( ) I don’t know

2. Be able to act on your wishes and separate his/her own feelings from yours.

   ( ) Yes  ( ) No  ( ) I don’t know

3. Knows you well and understands what’s important to you.

   ( ) Yes  ( ) No  ( ) I don’t know

4. This person is willing to talk with you now about sensitive issues and will listen to your wishes.

   ( ) Yes  ( ) No  ( ) I don’t know

5. This person likely to be available long into the future.

   ( ) Yes  ( ) No  ( ) I don’t know
6. This person is willing to be an advocate for my wishes and is able to handle conflicting opinions between family members, friends and medical personnel.

( ) Yes  ( ) No  ( ) I don’t know

7. The person (s), I choose to designate as my Helper (agent for health-care) is:

8. What is his or her relationship to you?

We would like to invite this person to join us for the last meeting. This session will provide opportunity for sharing and to talk about the importance of being a good agent for health-care.

Session Two: Having Caring Conversations with My Family about My End-of-Life Wishes

Introduction

As we get older, some of us make a Will or Living Trust; others plan their funeral or memorial service and some will tell their closest relative or trusted friend about their last wishes. However, most of us never complete one very important task: we do not share with our families and doctors our wishes and what medical procedures we want if we face a life-threatening situation or, if at the end of our lives, we are unable to communicate. In fact, fewer than 30 percent of Americans have decided what type of healthcare treatment they might want, or not want, if they became unable to communicate. Hispanics are about one-third as likely as Caucasians to have expressed their health-care wishes in case they are unable to communicate.

Those of us who want to be prepared for the future and take the time to make preparations listed above, do so to spare our loved ones the stress of having to guess what we want when we become too sick to communicate our wishes. If you can begin to talk
about the end-of-life, you will have made a significant contribution to your family and you will discover important information for yourself. Having these conversations includes understanding hopes and fears associated with illness and dying. Talking about what you wish for your end-of-life care is the single most important thing you can do to help your family and those you care most about cope with inevitable loss.

Benefits of Advance Planning for Future Health-care Choices

1. Giving the gift of guidance, confidence and strength to those closest to you in the event that you become ill and they have to speak for you.

2. Learning about and choosing from the options available for your future healthcare in a variety of situations.

3. Provide clear instructions for health-care providers and others who may have to make decisions for you.

4. Ensuring that you receive medical care that supports your Christian values.

Advance Directives

Advance directives are broadly defined as documents mentally competent people write to help guide their future medical care decisions in advance of a time when they may no longer be able to directly communicate their wishes. In California, the only legal requirement for advance directives to be valid is the person’s signature and date. If the person is unable to sign, someone can sign the directive in the individual’s presence. Advance directives must be witnessed by two qualified adults or notarized. California recognizes two types of advance directives:
1. The instructions for health-care is a legal document which tells your doctor or other health care providers whether or not you want life-sustaining treatments or procedures administered if you are in a terminal condition or a permanent unconscious state.

2. Power of attorney for health-care is a legal document that designates one or more adults to act as your agent for health-care if you should become temporarily or permanently unable to make those decisions associated with end-of-life medical care.

You can select a member of your family or a close friend as your agent for health-care. If you select your spouse and then become divorced, the appointment of your spouse as your agent is revoked. A supervising health care provider, operator or employee of any health-care institution, community or residential care facility cannot be appointed as your agent unless they are related to you by blood, marriage or adoption.

According to the Christian Medical and Dental Associations the following assumptions underlie the use of advance directives:

1. Many of us will face loss of decision-making capacity.

2. The patient and the family will discuss the health-care preferences and will write them down in advance.

3. Selecting an agent for health-care can avoid confusion and heartache for the family and provide better care for all concerned.

4. Every medical intervention that can be done need not be done.

5. Treatment decisions require informed consent by you or someone on your behalf.
Medical Terms Related to Your End-of-Life Care

The following definitions of medical terms related to end-of-life care are intended to serve as a guide in discussing your health-care needs and wishes with your family and doctors. Those responsible for your medical care need to know what your end-of-life wishes are in case you are unable to express them. Talk to your doctor on the kinds of medical decisions you are likely to face because of your own medical history. Think about when would be a good time to talk to your doctor. It may be during your next scheduled appointment. It is very important to talk to your doctor to ensure that the medical team will honor and respect your instructions wishes and regarding your end-of-life care.

1. Life support treatment is defined as any medical procedure, device or medication administered with the intent to keep the patient alive. Life support treatment includes: medical devices put in to help the patient breathe, food and water supplied by medical device (tube feeding), cardiopulmonary resuscitation (CPR), major surgery, blood transfusions, dialysis and anything else meant to sustain life.

2. Cardiopulmonary resuscitation (CPR) refers to medical procedures used to restart a patient's heart and breathing when the heart stops beating and/or lungs unexpectedly stop working. Patients often need an electrical shock to help restart the heartbeat. The medical team presses on the chest to help pump blood, and uses artificial breathing devices to supply oxygen to the lungs. Artificial breathing means the doctor puts a tube in the windpipe. A machine breathes for the patient through the tube. Without CPR, the heart will unlikely start beating again and the patient will probably die.
3. DNR (Do Not Resuscitate) order states that no effort, such as CPR (Cardio Pulmonary Resuscitation) should be made to save the patient's life if the heart stops beating or if the person stops breathing. The DNR tells the physician and other healthcare professionals that the patient is ready to accept death and that additional life-saving intervention is not desired.

4. Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive. Artificial feeding is a way of getting calories and nutrients into the body when a person cannot eat naturally. It may involve the use of a tube inserted into the stomach through the nose, or inserted surgically through the skin and stomach wall. The tube can deliver nutrition, fluids and medications.

5. For centuries, determining death was a straightforward matter. When a person's heart stopped and the person breathing ceased, the person was declared dead. However, with modern technology these functions can be maintained even when all brain activity ceases. Brain death is the irreversible end of all brain activity including involuntary activity necessary to sustain life due to total death of the cerebral neurons following loss of blood flow and oxygenation. This event presents the family and medical personnel with significant ethical and medical decisions, if no advance preparation has been made and people understand that there is no recovery from brain death.

6. In most states, a terminal condition is defined as a status that is incurable or irreversible and in which death will occur within a short time.

7. The American Academy of Neurology defines a persistent vegetative as a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness
and physiologic sleep/wake cycles but at no time is aware of himself/herself or the environment.

8. Palliative care refers to care directed toward the quality of life of patients who are facing a life-threatening illness. Particular attention is given to the relief of pain and other symptoms, psychological and spiritual needs of the patient are addressed, and medical professionals provide support for the patient and family.

9. Hospice care is a care approach available to a person who is terminally ill (death likely within six months). Its focus is not on curing the illness, or shortening or prolonging life, but on comfort and quality of life. Care focuses on symptom and pain management, keeping the person comfortable, and providing psychological and spiritual support to the patient, family and caregivers.

10. Organ donation is the process of removal and transplantation of viable organs from donor to recipient. Organ donation from one person can enhance the lives of 50 people. Organs that can be donated include heart, kidneys, pancreas, lungs, liver, and intestines. Tissues that can be donated include cornea, skin and bone marrow. Organs and tissue considered for transplant must receive blood until they are removed from the donor’s body. Therefore, it may be necessary to place the donor on a breathing machine temporarily or provide other organ-sustaining treatment. Organ donation does not change funeral plans. The body of an organ donor can still be shown at a memorial service.

Medical, Spiritual, and Emotional Issues at End-of-Life Care

Technology has advanced to a point where patients with no hope of recovery can be kept alive for long periods. This makes it more important than ever for people to
express how they feel about prolonging life and deciding what kind of care they would want if they become unable to make their own decisions.

Imagine that suddenly without warning you are struck down by a life-threatening illness and are in an intensive care unit of a hospital. You can no longer recognize people or communicate with anyone. Despite the best medical treatment, your doctors believe you probably will not leave the hospital alive. What would be your goals for medical treatment? The following three scenarios are intended to help you think about the kind of treatment you would like to receive. You may skip any question you are not ready or comfortable to answer.

1. Due to my life-threatening illness, I am likely to die within a short period of time. My mind is not working well enough to make decisions for myself. Life support treatment would only delay the moment of my death. You are asked to circle the responses below that best describe what you wish the medical team to do for you.

<table>
<thead>
<tr>
<th>I want to have life-support treatment and receive all medical care available to prolong my life.</th>
<th>Not Important</th>
<th>No Opinion</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
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<tr>
<th>I do not want life-support treatment, except that I do want to receive artificial feeding and fluids.</th>
<th>Not Important</th>
<th>No Opinion</th>
<th>Very Important</th>
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<table>
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<tr>
<th>I do not want to receive life-support treatment. If it has been started, I want it stopped. I want comfort care only.</th>
<th>Not Important</th>
<th>No Opinion</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
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<td></td>
<td>1</td>
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</tbody>
</table>
2. My doctor and another health-care professional both decided that I am in a comma or a persistent vegetative state. I am brain dead and life support treatment would only delay the moment of my death. What would I wish the medical team do? Please circle the number that best expresses its importance to you.

<table>
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<td>1</td>
<td>2</td>
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</tr>
</tbody>
</table>

3. Because of my life-threatening illness, my doctor and another health care professional both decide that I have permanent and severe brain damage, (for example, I can open my eyes, but cannot speak or understand). I am not expected to get better. Life support-treatment would only delay the moment of my death. What would I wish the medical team do? Please circle the number that best expresses its importance to you.
I want to have life-support treatment and receive all medical care available to prolong my life.  

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<td>2</td>
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</table>

4. You are asked to think of an event that is relevant to your end-of-life care. For this particular situation, would you want to receive life-support treatment to prolong your life or would you want comfort care only?  

People have personal priorities and spiritual or religious beliefs and rituals that affect their medical decisions. To make your values and beliefs more clear, please continue to focus on the responses you want when you are close to death. For each situation where you have a view, please circle the number that best expresses its importance to you.
<table>
<thead>
<tr>
<th>I wish for my family and friends to know that I do not fear death itself. Christ died for me and I will have eternal life.</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>I wish to have my family and friends know that I love them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I wish to be forgiven for the times I have hurt my family, friends, and others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I wish for my family and friends to know that I forgive them for when they may have hurt me in my life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>If I show signs of depression, nausea, shortness of breath, I want my caregivers to do whatever they can do to help me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I wish to know options for hospice care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I wish to have my hand held and to be talked to when possible, even if I don’t seem to respond to the voice or touch of others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I wish that my pastor be notified and have the members of my church told that I am sick and asked to pray for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I wish to have religious readings read and prayers said for me when I am near death.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
When possible, I wish to have my favorite music played until my time of death.  

I wish my family and friends and caregivers to respect my wishes even if they don’t agree with my choices.

I have the following additional wishes or thoughts. Please list below:

**After Death Decisions to Think About Now**

After the death of a loved one, family and friends are often left with difficult decisions. You can help ease the pain and anxiety by making choices and letting your family know your wishes in the matters listed below.

1. Would you consider donating viable organs for transplant?

   ( ) Yes   ( ) No

   If yes, which organs would you consider donating?

2. Would you consider donating viable tissues for transplant?

   ( ) Yes   ( ) No

   If yes, which tissues would you consider donating?

3. After my death, I would like my body to be (check one)

   ( ) Buried   ( ) Cremated

4. I wish for my memorial service to include the following: (Any favorite music, songs, reading or other specific request that you have)
Suggestions of How to Talk to Your Family About Your End-of-Life Care Wishes

Having caring conversations with your family can provide them peace of mind as they seek to fulfill the desires you have for end-of-life issues. We encourage you to talk and share with your family the information you expressed above. Your wishes about your future health-care or personal care can be set out in any form (writing, verbally, audiotape or videotape). However, we encourage you to write your wishes on the attached advance directive document.

Prior to completing an advance directive, prayerfully consider God’s will for your life and end-of-life care. Family, clergy, and other Christian advisors can assist if you are uncertain about the application of biblical principles to your particular situation. By signing an advance directive now you will relieve your family of any the future burden of having to make difficult medical decisions on your behalf without knowing your wishes. You can change your end-of-life care wishes and instructions any time as long as you are mentally aware and still capable of making a decision.

After you have filled out your own end-of-life care wishes, you will have an easier time telling your family and friends what you want. The following are suggestions for how to talk with your loved ones:

1. Start off with the topic that you are most comfortable discussing. You don’t have to start with a discussion about harder issues such as life-support treatment.

2. Take time to discuss your wishes and instructions so your family understands how important your decisions are to you.

3. Make sure you have copies of your advance directives to give to those you are talking with, and ask them to bring their copy to the hospital if you get sick.
4. Talking with your family and friends about end-of-life issues before you are seriously ill is a good way to clarify what you want or don’t want for your medical care. It also offers opportunity for others to ask questions and understand the decisions you made.

5. Make sure you discuss your wishes and instructions with the person you pick to be your agent for health-care.

We want to invite your agent for health-care to join us for the last meeting. This session will provide opportunity for sharing. We will talk about the importance of being a good agent for health-care.

Session Three: Sharing and Feedback

“What do we live for if not to make life less difficult for each other?”
George Eliot (Mary Ann Evans)

Introduction

Without an advance directive, you may have no control over important medical care decisions if you are seriously ill. Therefore, it is important to identify your preferences for life-support treatment. Everyone has different wishes and yours won’t be followed unless you make them clear. For example, your dying process could be artificially prolonged even though you may have wanted a natural death. The best time to fill out an advance directive is before you face a health-crisis. Talking about your preferences for treatment will save your family the heartache of having to make decisions for you without knowing your wishes. It will make a difficult time more manageable and your family will feel reassured that they respect your wishes.
Time of Sharing and Feedback

1. Did you complete the advance directive document given to you at the last meeting?

( ) Yes  ( ) No

If no, what hindered you?

2. Did you talk to your family about end-of-life issues?

( ) Yes  ( ) No

If yes, what was their response?

If no, what hindered you?

How to Be a Good Agent for Health-Care

You have been asked by a family member or friend to be his or her agent for health-care. This means you have the power to make medical decisions for this person in case she or he ever becomes too sick to communicate. As an agent for health-care, you are not only the conveyor of the individual’s wishes and instructions, but also you are someone whom this person trusts and perhaps loves. In the act of selecting you as an agent for health-care, your family member or friend empowers you with interpretative discretion. You are responsible to assess and make moral judgments for end-of-life medical situations on behalf of your loved one or friend.

As an agent for health-care, your job is to see that this person’s wishes are followed. Know the person’s wishes ahead of time. Ask questions when discussing the individual’s wishes so that you understand what he or she would want in various situations. If for some reason you can’t follow these wishes, ask that person to choose someone else to be the agent for health-care.
The doctors and nurses caring for the person need to know who you are and how to reach you. Ask questions of the doctors and nurses and monitor the person’s care to assure that the individual’s wishes are honored.

An agent for health-care has an important responsibility, when the time comes for you to step in, your task will include asking questions and getting solid answers, developing and adjusting care plans, and following through.

What to Do by the Bedside

First of all, just being there with your loved one is the most important thing you can do. Do not worry about having the right things to say. People who are dying might want their loved ones to:

1. Hold their hands, and talk to them even if your loved does not respond to your voice.
2. Play some music for them.
3. Read religious readings and pray for them.
4. Show photographs and tell stories of people you both know.
5. Talk about current events in the news, in your family or at church.
6. Listen to them, even if what they say does not make sense.
7. Assure them that they are not a burden and tell them you will always remember them.
8. Do not say things to them that are not true, such as they are going to get better when the doctor has told you differently.
Your Preparation for the Dying Process

From a Christian's perspective, the most important thing you can do to prepare for the dying process is to become personally acquainted with the One who came as a child in Bethlehem and accept him as your personal Savior. To know Jesus as one’s personal Savior will bring peace and the assurance of eternal life.

Another significant way you can prepare for the dying process is to build and maintain healthy relationships with family members, friends, and church members. It is important to acknowledge that the dying process is not only the experience of an individual; it is the experience of a community. When death arrives, the family misses the one who has died. People long to be with the person they loved; however, for a Christian, there is the assurance that the separation is only temporary. At time of death, believers do not grieve like others who have no hope (1 Thess 4:13). Believers are consoled by the “blessed hope”, the hope of the resurrection.

Program Evaluation

Response to the following questions is appreciated. Your evaluation will assist us in future seminars. Your information will be kept confidential.

1. Personal Data (Circle only one)

   How old are you?

   ( ) 60 – 65   ( ) 66-70   ( ) 71 – 75   ( ) 76-80   ( ) More than 81

   Are you: ( ) Male   ( ) Female

   Are you currently:

   ( ) Married   ( ) Separated   ( ) Divorced   ( ) Single   ( ) Widowed
2. Please circle the number that best expresses your opinion.

Making plans for end-of-life care is part of being a Christian steward.

1  Strongly Disagree  2  Not sure  3  Agree  4  Strongly Agree

If I am not able to make my own health-care decisions, I would like to have someone I trust to make those decisions for me

1  Strongly Disagree  2  Not sure  3  Agree  4  Strongly Agree

3. Did you talk to your family about end-of-life issues?

( ) Yes  ( ) No

If yes, how would you rate their response?

1  Very Poor  2  Poor  3  Fair  4  Good  5  Excellent

If no, what hindered you?

4. Have you signed an agent for health-care (power of attorney for health-care) advance directive document? (Circle your answer)

( ) Yes  ( ) No  ( ) I don’t know

5. Have you completed the instructions for health-care (Living Will) advance directive document? (Circle your answer)

( ) Yes  ( ) No  ( ) I don’t know

6. How would you rate the overall effectiveness of the seminar? ?

1  Very Poor  2  Poor  3  Fair  4  Good  5  Excellent

6. Please answer one of the following statements:

I am glad that I came to this seminar because

99
Introducción

La tecnología médica puede prolongar la vida del ser humano casi indefinidamente. Esto ha traído como resultado que personas moribundas en capacidad de decidir su cuidado médico, se encuentran en situaciones en que deben decidir si desean o rehúsan una intervención médica para prolongar la vida y de esta manera postergar el momento de la muerte. Lamentablemente muchas personas no siempre tienen la capacidad mental de hacer estas decisiones. Por ejemplo, pacientes inconcientes o confundidos que no pueden expresar el tipo de intervención médica que desean. En estos casos, la familia junto con el equipo médico debe tomar decisiones que estén de acuerdo con lo expresado anteriormente por el paciente. Lo complicado es que en muchos casos las personas no han expresado con anticipación sus deseos e instrucciones sobre el cuidado médico al final de la vida.
Planificamos con anticipación eventos tales como fiestas de cumpleaños, celebraciones de aniversario y vacaciones. A pesar de que planificar es algo que hacemos diariamente, muchas veces dejamos de planificar con anticipación una de las decisiones más importantes que podamos hacer: nuestro cuidado médico. Planificar con anticipación nuestro futuro cuidado médico es una decisión sabia y responsable. Esto incluye pensar en el cuidado médico que quisieras recibir en caso de que estés demasiado enfermo para poder comunicar tus deseos y discutirlos con aquellas personas que están cerca de ti. De esta manera, tus seres queridos pueden entender y aceptar que tus decisiones son importantes.

El hacer decisiones anticipadas de tu cuidado médico y compartir estas instrucciones con tus seres queridos es realmente un regalo que le otorgas a tu familia. Al conversar con tu familia acerca de tus preferencias del cuidado médico, les evitarás un dolor a tus familiares en caso de que ellos tengan que tomar decisiones sobre tu cuidado médico sin saber tus deseos e instrucciones finales. Si expresas tus deseos a tus seres queridos harás que un momento tan difícil, en el futuro se convierta en algo un poco más fácil de soportar, porque tu familia sabrá que estará respetando tus deseos finales.

**Propósito Del Seminario**

El propósito de este seminario es animar a las familias para que tengan conversaciones prácticas sobre la planificación anticipada del cuidado médico dentro del contexto de la mayordomía cristiana. Al terminar el seminario, Usted estará en capacidad de:

1. Aplicar principios cristianos en su planificación sobre el cuidado al final de la vida.
2. Entender el significado y poder designar a una persona como su Representante Legal Para Las Decisiones Del Cuidado Médico.

3. Usar ciertas técnicas para poder participar en conversaciones prácticas sobre tu cuidado médico al final de la vida con tus seres queridos.

La Muerte, Un Enemigo Vencido

Más de dos millones de personas mueren anualmente en los Estados Unidos. Al final de la vida, cada persona tiene una historia diferente. Para algunos la muerte puede venir de una manera inesperada, para otros de una manera lenta. Para algunas personas mayores, el cuerpo se debilita mientras que la mente permanece alerta. Para otros, la muerte los debilita pero se conservan bien físicamente. A menos que Jesús regrese pronto, cada uno de nosotros tendrá que enfrentar la muerte. El mensaje cristiano es claro en referencia a este enemigo misterioso que llamamos muerte. No tenemos que especular acerca de lo que pasará después de la muerte. Jesucristo murió y resucitó de entre los muertos. Mas que esto, Jesús prometió que todos los que creen en él tendrán la seguridad que van a ser resucitados entre los muertos.

La enseñanza del apóstol Pablo en este tema es la siguiente: “El Señor mismo, con voz de mando, con voz de arcángel y con trompeta de Dios, descenderá del cielo. Entonces, los muertos en Cristo resucitarán primero. Luego nosotros, los que vivimos, los que hayamos quedado, seremos arrebatados juntamente con ellos en las nubes para recibir al Señor en el aire, y así estaremos siempre con el Señor.” (1 Tesalonicenses 4:16-17). Los creyentes tienen la seguridad que la muerte no tiene la última palabra. Dios los va a resucitar de los muertos y los llevará a una nueva vida de la misma manera que hizo al resucitar a Jesús.
Una Muerte Tranquila

Algunas personas piensan que la muerte ideal es acostarse una noche y simplemente no despertar al día siguiente. Muchos de nosotros probablemente definiríamos la muerte ideal como morir en paz, concientes que nuestro fin se acerca, teniendo la satisfacción de que hemos alcanzado la mayoría de los objetivos que nos hemos propuesto en nuestras vidas. El Dr. John Dunlop, un médico cristiano, identifica los siguientes principios de una muerte tranquila:

1. Es la trayectoria de una vida de fe, que comienza temprano en la vida. No debe existir ninguna diferencia entre la fe que vivimos diariamente y la fe con la cual morimos. Un creyente encuentra el valor supremo de su existencia no en esta vida terrenal sino en su relación eterna con Dios.

2. Incluye planificar con anticipación. Esto significa una introspección profunda de nuestros valores y el poder compartirlos con nuestra familia y la persona que hemos designado como el representante legal sobre las decisiones de los cuidados médicos. Las instrucciones anticipadas del cuidado médico deben ser consistentes con nuestra fe y nuestros principios cristianos.

3. Restablecer relaciones que necesitan reconciliación. Hay cuatro palabras que muchas personas frecuentemente dicen al final de su existencia: Te quiero, Gracias, Te Perdono y Perdóname.

4. Se produce después que dejamos de aferrarnos a las cosas y valores de este mundo para aceptar las cosas eternas.

5. Es apacible, por que la persona moribunda confía en la resurrección de entre los muertos y la promesa de la vida eterna en la presencia de Dios.
Mayordomía Al Final De La Vida

Al pensar en la mayordomía, la figura de un discípulo fiel que cuida y administra todo que Dios le ha dado en las diferentes etapas de su vida es muy apropiada. La mayordomía cristiana tiene que ver con las decisiones que tomamos y como estas decisiones nos afectan a nosotros y a otras personas. La vida humana es un don precioso y como tal debemos ser buenos mayordomos de ella. Los cristianos somos mayordomos de nuestros cuerpos, salud y los recursos que están a nuestra disposición. Por lo tanto, como creyentes somos responsables ante Dios por nuestras decisiones de nuestro estilo de vida y del cuidado de la salud. Desde esta perspectiva, la mayordomía al final de la vida incluye una planificación anticipada de nuestro cuidado médico con fundamentos basados en las Sagradas Escrituras. Expresar nuestros deseos con anticipación en relación a situaciones que tienen que ver con el final de la vida forma parte de la mayordomía cristiana.

Las siguientes pautas que pueden ayudarle a Ud. en su planificación con anticipación de su cuidado médico al final de la vida:

1. La verdad no se le debe ocultar al paciente moribundo, sino compartirla con amor cristiano y sensibilidad, tomando en cuenta las circunstancias personales y culturales del paciente (Efesios 4:15).

2. Las personas moribundas deben ser tratadas con respeto y dignidad.

3. El sufrimiento humano no tiene mérito o valor expiatorio.

4. Una persona capacitada para decidir, determinará si acepta o rechaza la intervención médica para prolongar la vida y que solamente posterga el momento de la
muerte. Tales personas no deben ser obligadas a someterse a tratamiento médico que consideren inaceptable.

5. Los cristianos generalmente se oponen a la práctica de eutanasia, el tomar la vida intencionalmente de una persona que está sufriendo o agonizando. Tampoco es necesario aceptar, u ofrecer todos los tratamientos médicos posibles que solamente prolongan el proceso de la muerte.

6. Permitir que el paciente muera como resultado de haber impedido intervenciones médicas que solamente prolongan el sufrimiento, y que postergan el momento de la muerte, es moralmente diferente a las acciones que tienen como primera intención tomar la vida directamente.

7. Tratamientos médicos para prolongar la vida se pueden omitir o suspender si solamente añaden sufrimiento al paciente, o prolongan el proceso de muerte innecesariamente.

8. Cuando se hace claro que la intervención médica no sanará al paciente, el objetivo principal de atención se desviará hacia el alivio de su sufrimiento.

**Pensar En Tu Cuidado Al Final De La Vida**

Las siguientes preguntas tienen el objetivo de hacerte reflexionar en el proceso de tomar decisiones y de comunicar estas decisiones del cuidado médico al final de tu vida con tus seres queridos y con las personas que estarán involucrados en tu cuidado médico. Puedes omitir cualquiera pregunta que no estés lista para contestar.

1. Si murieras hoy, ¿tendrías la seguridad de la vida eterna en Jesucristo?
2. Si pudieras planificar las circunstancias en que te encontrarías al final de tu vida, ¿Qué escogerías?

- ¿Qué personas te gustaría que estuvieran a tu lado?
- ¿En qué lugar te gustaría estar?
- ¿Cuáles son tus temores o ansiedades cuando piensas del final de tu vida?
- ¿Cómo te gustaría que te recordaran?

El Agente Para El Cuidado De La Salud

Si no estuvieras en capacidad de expresar o de tomar decisiones sobre tu cuidado médico, a quien escogerías para que tome esas decisiones por ti? _________________

Llamemos a esta persona tu ayudante. En términos legales, tu ayudante se llama en California “Un Agente Para El Cuidado De La Salud.” Esta persona o personas deben ser mayores de 18 años. Las personas más adecuadas para esta responsabilidad, son aquellas en quien tú confías y te comunicas bien. Las siguientes preguntas te pueden ayudar en la selección de esta persona como tu Agente Para El Cuidado De La Salud:

1. ¿Estaría esta persona dispuesta a representarte a ti?
   ( ) Si ( ) No ( ) No sé

2. ¿Estaría esta persona dispuesta a llevar a cabo tus deseos y separar sus sentimientos e ideas personales de los tuyos?
   ( ) Si ( ) No ( ) No sé

3. ¿Conoces bien a esta persona y el ó ella entiende lo que es importante para ti?
   ( ) Si ( ) No ( ) No sé
4. ¿Estaría esta persona dispuesta a hablar contigo de temas relacionados con el fin de la vida y crees que prestará atención cuando tu estés expresando tus deseos e instrucciones del final de la vida?

( ) Si  ( ) No  ( ) No sé

5. ¿Estará esta persona siempre disponible en el caso de que te encuentres incapacitada(o) para expresar tus deseos del cuidado médico?

( ) Si  ( ) No  ( ) No sé

6. Consideras que esta persona puede ser un(a) defensor(a) de tus deseos e instrucciones con el personal médico y otros miembros de tu familia para estar seguro(a) de que tus deseos sobre el cuidado médico al fin de tu vida sean respetados.

( ) Si  ( ) No  ( ) No sé

7. La persona(s) a quien me gustaría designar como mi Agente para mi cuidado médico es: ___________________________________________________

8. ¿Qué relación tiene esta persona con Usted?

**SESIÓN II**

**Conversaciones Amorosas Con Mi Familia**

**Acerca De Mis Deseos Al Final De La Vida.**

**Introducción**

A medida que envejecemos, muchos de nosotros planificamos con anticipación el final de nuestra vida, al redactar nuestro testamento y planificar nuestro propio servicio fúnebre. Sin embargo, muy pocos de nosotros tenemos una conversación franca con nuestros seres queridos, amigos cercanos y doctores acerca de nuestras instrucciones...
sobre el cuidado médico al final de la vida, en caso de que no podamos expresar nuestros deseos. De hecho, menos del 30 por ciento de los americanos han decidido que tipo de tratamiento médico le gustaría recibir, en caso de que no se puedan expresar sus deseos al final de su vida. Esta proporción es un tercio menor entre los hispanos.

Aquellas personas que planifican con anticipación sus decisiones futuras del final de su vida, lo hacen con el fin de facilitar a sus seres amados, el proceso de tomar decisiones finales, en caso de que ellos tengan una enfermedad terminal, o si al fin de sus vidas no están en capacidad de expresar sus deseos del cuidado médico. Al conversar con tus seres queridos, acerca de tus deseos e instrucciones para el final de la vida, te estás haciendo un gran favor a ti mismo y a tu familia. En este proceso de reflexión encontrarás, que tus valores influyen en tu comprensión del proceso de la muerte y de la tensión, que existe entre los sentimientos de temor y de esperanza, que rodean las enfermedades y la muerte. Conversar con tu familia acerca de tus deseos e instrucciones del final de tu vida es un regalo invaluable, que le dejarás a tus seres queridos.

**Beneficios de Planificar Con Anticipación Tus Decisiones Sobre Tu Futuro Cuidado Médico**

1. Debes otorgar a tus seres queridos el regalo de la orientación, la confianza y la fortaleza necesaria, para que estén consientes y respeten tus deseos, en caso que te encuentres tan enfermo que ellos tengan que tomar decisiones del cuidado médico por ti.

2. Al analizar las diferentes opciones disponibles para el cuidado al final de la vida, podrás escoger la que tú consideres más apropiada para tu futuro cuidado médico.
3. Proporciona instrucciones específicas sobre tus deseos al final de tu vida al personal médico y a otras personas, que pudieran estar involucradas en tu cuidado médico, para asegurarte que respetarán tus instrucciones.

4. Al planificar tu futuro cuidado médico, estarás pendiente que éste refleje tus principios y valores cristianos.

**Directiva Anticipada De La Atención De La Salud**

La directiva anticipada de la atención de la salud es un documento, en el cual personas mentalmente competentes para tomar decisiones, redactan sus instrucciones del cuidado al final de la vida, para orientar su futuro cuidado médico en caso de que se encuentren incapacitadas, para expresar sus deseos e instrucciones finales. En California, el único requisito legal para que un documento de directiva anticipada de la salud sea valido: es la firma de la persona y la fecha cuando firmó el documento. El documento de directivas anticipadas debe ser firmado en presencia de dos testigos calificados o certificado ante un notario público. El estado de California reconoce dos tipos de directivas anticipadas:

1. Las instrucciones sobre el cuidado de la salud es un documento legal, que le dice a su doctor y otras personas involucradas en su cuidado médico, instrucciones específicas sobre cualquier aspecto de la atención de su salud, especialmente si usted desea o rechaza procedimientos para el mantenimiento de la vida, en caso que sufra de una enfermedad terminal o esté en una condición de estado vegetativo persistente.

2. El poder de representación para cuidados de salud es un documento legal, que le permite a usted nombrar una o más personas adultas para que actúen, como su Agente
para el cuidado de la salud en caso de que usted, ya sea temporal o permanentemente, se
encuentre incapacitado para tomar decisiones relacionadas con su cuidado médico al final
de la vida. Usted puede elegir a un miembro de su familia o un amigo(a) cercano. Si
usted elige a su esposo(a) y después se divorcian, la designación de esa persona como su
agente queda anulada. El profesional de la salud que supervisa su atención médica, el
dueño o empleados de la institución de salud, en la cual usted está recibiendo su atención
médica, no puede ser designado como su agente a menos que esta persona esté
emparentada con usted por consanguinidad, adopción o matrimonio.

De acuerdo con la Asociación de Médicos y Odontólogos Cristianos, las
siguientes suposiciones son la base para el uso de las directivas anticipadas de la salud:

1. Muchos de nosotros perderemos la facultad de tomar decisiones.
2. El paciente hablará con su familia acerca de sus preferencias del cuidado
medico y las escribirá con anticipación.
3. Al elegir a un Agente para el cuidado de la salud, le evitarás un dolor a tu
familia en caso de que tengan que tomar decisiones, sin saber tus deseos e
instrucciones finales.
4. Cada intervención médica que se puede hacer no es necesaria realizarla.
5. Las decisiones para el tratamiento médico requiere su consentimiento o el de
otra persona en su nombre.

Terminología Médica Relacionada con su Cuidado al Final de la Vida

Los siguientes conceptos médicos relacionados con el cuidado del final de la vida
tenían como finalidad, servirle como guía cuando converses tus necesidades y deseos
médicos con tu familia y doctores. Aquellas personas que son responsables de tu cuidado
médico, deben saber tus deseos del cuidado al final de la vida con anticipación, en caso de que llegues a estar incapacitado para expresarlos. Conversa con tu médico sobre las posibles decisiones del cuidado de tu salud, que pudieras enfrentar en el futuro debido a tu historia médica. Piensa en el mejor momento para conversar con tu médico. Podría ser en tu próxima visita al consultorio. Es muy importante que converses con tu doctor, para que de esta manera tengas la seguridad que el equipo médico respetará y honrará tus deseos e instrucciones.

1. El uso de equipo y de intervenciones médicas para el mantenimiento artificial de la vida, tienen el fin de mantener al paciente crónico vivo e incluye la utilización de un respirador, cuando el paciente ya no puede respirar por sí mismo, un tubo de alimentación cuando el paciente crónico ya no puede masticar ni tragar la comida, resucitación cardiopulmonar, cirugía mayor, transfusiones de sangre, diálisis y cualquier otro tratamiento que tenga el objetivo de mantener al paciente con vida.

2. La resucitación cardiopulmonar (RCP) es un procedimiento médico de emergencia, usado para tratar de reiniciar la actividad cardíaca y la respiración. La resucitación cardiopulmonar consiste en soplar aire por la boca y presionar sobre el pecho. Si este procedimiento no revive a la víctima, el equipo de emergencia de la ambulancia o del hospital comenzará el mantenimiento de vida avanzada, que incluye la colocación de un tubo en la tráquea, la aplicación de descargas eléctricas al pecho y la inyección de medicamentos en las venas. El paciente podría necesitar un respirador para ayudarle a respirar durante un tiempo indeterminado.

3. Orden Médica de No Resucitación. Esta orden médica establece que no se debe realizar resucitación cardiopulmonar si la respiración cesa o el corazón deja de latir.
4. Si un paciente no es capaz de ingerir alimentos o tomar líquidos por causa de un problema médico, los doctores utilizan la hidratación y nutrición artificial, con el fin de proveer al paciente las calorías y nutrientes necesarias para conservarle la vida. La nutrición artificial se realiza a través de un tubo plástico, que se puede insertar a través de la nariz hacia el estómago o utilizando un procedimiento quirúrgico, en el cual se le inserta al paciente un tubo plástico a través de la piel, para colocarlo en la pared del estómago. Líquidos nutrientes y medicinas se administran a través del tubo plástico.

5. Tradicionalmente se ha definido la muerte como el cese de todas las funciones corporales, inclusive la respiración y el latido cardíaco. Debido a que la tecnología moderna permite, que un individuo conserve la actividad respiratoria y el flujo sanguíneo artificialmente, se hizo necesaria una mejor definición de la muerte, tomando en consideración el concepto de muerte cerebral o encefálica. Según este criterio, la muerte cerebral es la pérdida irreversible de toda actividad cerebral, incluyendo actividades involuntarias necesarias para mantener la vida, debido a la muerte de las neuronas por causa de la pérdida del flujo sanguíneo y de la oxigenación. Sino se tiene claro el concepto que una persona diagnosticada con muerte cerebral está realmente muerta, se puede convertirse en un dilema ético para la familia, que tiene que tomar decisiones del cuidado médico del final de la vida de su ser querido.

6. En la mayoría de los estados de la Unión Americana, se define una enfermedad terminal como un padecimiento incurable o irreversible, en el que la muerte puede producirse tras un breve lapso.

7. Según la Academia Estadounidense de Neurología, un estado vegetativo persistente es “una forma de inconsciencia permanente en la que el paciente permanece
con los ojos abiertos y atraviesa periodos de alerta y ciclos fisiológicos de sueño/vigilia, pero sin que esté consciente de sí mismo ni del ambiente que lo rodea”

8. El tratamiento paliativo se enfoca en el cuidado integral y comprensivo de pacientes, diagnosticados con enfermedades incurables con el propósito de mejorar la calidad de vida del paciente. Las intervenciones paliativas se hacen con la intención de aliviar el sufrimiento, manejar las complicaciones médicas, controlar los síntomas de disconformidad y prestar atención a las necesidades psicológicas y espirituales, tanto del paciente como el de los familiares.

9. Hospice es un programa integral, que se ofrece a las personas que se encuentran en estado terminal (probablemente mueran en un periodo no mayor de seis meses). El objetivo de este programa no es curar la enfermedad, ni acortar o prolongar la vida sino ofrecer confort y mejorar la calidad de vida del paciente. Para lograr este objetivo un equipo de profesionales de la salud une esfuerzos a fin de controlar los síntomas de disconformidad y manejar los dolores físicos, psicológicos, sociológicos y espirituales que el paciente pueda experimentar tanto el paciente como la familia.

10. La donación de órganos y tejidos sanos de una persona para trasplantarlos en otras. Los especialistas dicen que los órganos de una persona donante pueden salvar o ayudar hasta 50 personas. Los órganos que se pueden donar incluyen: Organos internos: riñones, corazón, hígado, páncreas, intestinos, pulmones. Tejidos: Córnea, piel, hueso y médula ósea. Para poder realizarse un trasplante, es necesario que circule la sangre en el cuerpo del donante. Es muy frecuente, que el donante sea colocado con un ventilador u otro tratamiento para mantener los órganos. El cuerpo de un donante muerto puede ser
velado y enterrado, de acuerdo a las costumbres religiosas y culturales del difunto y sus familiares.

Asuntos Médicos, Espirituales y Emocionales Relacionados Con

El Cuidado Al Final De La Vida

La tecnología médica ha avanzado a tal extremo que es posible mantener pacientes, que no tienen probabilidades de recuperarse vivos por largos periodos de tiempo. Por eso, es importante que las personas expresen sus preferencias sobre el tratamiento médico, para prolongar la vida y las decisiones sobre su cuidado, que quisieran recibir en caso de que no puedan tomar decisiones por ellos mismos.

Imagínense que inesperadamente te diagnostican una enfermedad terminal, y te internan en una unidad intensiva de un hospital. A pesar del avance de los tratamientos y la tecnología médica disponibles, los doctores que lo están atendiendo pronostican que probablemente no va a salir con vida del hospital. Si pudiera decidir sobre su cuidado médico, ¿Qué le gustaría que los profesionales de la salud hicieran? Los siguientes tres escenarios tienen como finalidad ayudarle a analizar el tratamiento médico, que le gustaría recibir al final de la vida. Puedes omitir cualquiera pregunta que no estés listo(a) para contestar.

1. Debido a que mi enfermedad es terminal, lo más probable es que fallezca en un breve período de tiempo. Mi mente no funciona para tomar decisiones. La intervención médica para el mantenimiento de la vida solamente retrasaría mi muerte. ¿Qué le gustaría que los doctores y las enfermeras hicieran? Por favor, marque el número que mejor expresa su opinión al respecto.
<table>
<thead>
<tr>
<th>Pregunta</th>
<th>No es importante</th>
<th>Me da igual</th>
<th>Muy importante</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quiero que me den todo el tratamiento médico posible, para mantenerme con vida y de esta manera prolongar mi vida.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>No quiero que me den ningún tipo de tratamiento médico para mantenerme con vida, con la excepción de hidratación y nutrición artificial.</td>
<td>1</td>
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<td>3</td>
</tr>
<tr>
<td>No quiero que me den ningún tipo de tratamiento médico para mantenerme con vida. Si han comenzado algún tratamiento, deseo que lo paren. Solamente deseo recibir tratamiento paliativo para mi condición.</td>
<td>1</td>
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2. Mi doctor y otro profesional de la salud determinan que estoy en estado de coma o en estado vegetativo persistente, del cual no se espera que despierte o que me recupere. Me diagnosticaron muerte cerebral y la intervención médica, para el mantenimiento de la vida solamente retrasaría el momento de mi muerte. ¿Qué te gustaría que el equipo médico hiciera? Por favor, marque el número que mejor expresa su opinión al respecto.
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<th><strong>Quiero que me den todo el tratamiento médico posible, para mantenerme con vida y de esta manera prolongar mi vida.</strong></th>
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3. Debido a que mi enfermedad es terminal, mi doctor y otro profesional de la salud determinan que sufro de un daño cerebral permanente (por ejemplo, puedo abrir los ojos, pero no puedo hablar o comprender lo que me están diciendo). El pronóstico de los médicos es que no hay esperanza de recuperación. El tratamiento médico para el mantenimiento de la vida solamente retrasaría el momento de mi muerte. ¿Qué le gustaría que el equipo médico hiciera en su caso? Por favor, marque el número que mejor exprese su opinión al respecto.
Quiero que me den todo el tratamiento médico posible, para mantenerme con vida y de esta manera prolongar mi vida.

No quiero que me den ningún tipo de tratamiento médico para mantenerme con vida, con la excepción de hidratación y nutrición artificial.

No quiero que me den ningún tipo de tratamiento médico para mantenerme con vida. Si han comenzado algún tratamiento, deseo que lo paren. Solamente deseo recibir tratamiento paliativo para mi condición.

4. Piense en alguna otra situación que pudiera presentarse en su cuidado médico al final de su vida. ¿Quisiera que le provean tratamiento médico, que le mantenga la vida o desearía recibir un tratamiento paliativo para esta situación?

Como seres humanos tenemos prioridades y valores personales, espirituales y creencias religiosas que sin lugar a dudas afectan nuestras decisiones médicas. Tomando en consideración estos valores y creencias que son importantes para usted, le pedimos que se enfoque en las siguientes situaciones que usted pudiera expresar al estar cerca de su muerte. Por favor, marque el número que mejor expresa su opinión al respecto.
<table>
<thead>
<tr>
<th>Deseo que mi familia y amigos sepan que no le tengo temor a la muerte. Estoy seguro(a) que Cristo me dará la vida eterna.</th>
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<tbody>
<tr>
<td>Deseo que mi familia y amigos sepan que los quiero mucho.</td>
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</tr>
<tr>
<td>Deseo que mi familia y amigos me perdonen por las veces que los he ofendido.</td>
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<td>3</td>
</tr>
<tr>
<td>Deseo que mi familia y amigos sepan que los perdonen por las veces que me han ofendido.</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Deseo que las personas que estén encargadas de mi cuidado médico, hagan todo lo posible para ayudarme si presento síntomas de depresión, nauseas o dificultad al respirar.</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Deseo que me notifiquen de la opción del hospice.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>En mi lecho moribundo, desearía que me tomen de la mano y me hablen, aunque parezca que no responda.</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Deseo que le notifiquen al pastor de mi iglesia que estoy enfermo(a) para que la iglesia ore por mi.</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Deseo que me lean lecturas religiosas y oren por mi cuando esté cerca mi muerte.</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Desearía que si es posible toquen mi música favorita al estar cerca mi muerte.</td>
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<td>3</td>
</tr>
<tr>
<td>Quiero que mi familia respete mis deseos aunque estén en desacuerdo con ellos.</td>
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<td>3</td>
</tr>
</tbody>
</table>
Tiene usted algún otro deseo o instrucción adicional.

Otras Decisiones Importantes

Después de la muerte de un ser querido, la familia y los amigos del difunto se enfrentan con algunas decisiones difíciles de tomar. Si usted notifica a sus familiares sus deseos en los siguientes asuntos, sin lugar a dudas les va ayudar aliviar el dolor y la ansiedad, que sus seres queridos posiblemente sientan al comenzar el proceso del duelo.

1. ¿Considerarías donar órganos de su cuerpo para transplantarlos a otro ser humano?
   ( ) Si   ( ) No

   Si su respuesta es positiva, ¿Qué órganos de su cuerpo estaría dispuesto a donar?

2. ¿Considerarías donar tejidos de su cuerpo para transplantarlos a otro ser humano?
   ( ) Si   ( ) No

   Si su respuesta es positiva, ¿Qué tejidos de su cuerpo estaría dispuesto a donar?

3. Al morir, desearía que mi cuerpo sea (por favor marque la respuesta apropiada)
   ( ) Enterrado   ( ) Incinerado

4. Desearía que mi servicio fúnebre incluya los siguientes aspectos: Mi música favorita, himno, alguna lectura o algún pedido especial que usted tenga.
   ( ) Si   ( ) No

   Si su respuesta es positiva, especifique lo que desea que sea incluido en el servicio fúnebre.
Sugerencias Para Conversar Con Tu Familia Acerca De Tus Deseos E Instrucciones Al Final De La Vida

El hacer decisiones anticipadas de tu cuidado médico y compartir estas instrucciones con tus seres queridos es realmente un regalo, que le otorgas a tu familia. Al conversar con tu familia acerca de tus preferencias del cuidado médico, les evitarás un dolor a tus familiares en caso de que ellos tengan que tomar decisiones sobre tu cuidado médico, sin saber tus deseos e instrucciones finales. Si expresas tus deseos a tus seres queridos harás que un momento tan difícil en el futuro, se convierta en algo más fácil de soportar, porque tu familia sabrá que estarán respetando tus deseos finales. Le animamos para que converse y comparta con su familia sus deseos acerca de su futuro cuidado médico. Estos deseos los puedes escribir, decirlo oralmente o grabarlo. Sin embargo, lo más recomendable es que escribas tus deseos en un documento como el de directivas avanzadas que te daremos al finalizar esta sesión.

Antes de completar su documento de directivas avanzadas, pídale a Dios que le guíe en el proceso de entender cual es la voluntad de Dios en su vida y en el proceso de planificación, para el cuidado médico al final de la vida. Si tienes alguna pregunta o incertidumbre en aplicar los principios cristianos, en tu planificación anticipada del final de la vida consulta con tu familia, tu pastor o un consejero cristiano. Usted puede cambiar sus instrucciones en cualquier oportunidad siempre y cuando tenga la capacidad mental de tomar este tipo de decisiones.

Después de haber analizado y escrito tus deseos para el final de vida, va a ser más fácil conversar con tu familia y amigos acerca de este tema. A continuación, presentamos una serie de sugerencias que te van a facilitar en tu conversación con tus seres queridos:
1. Empiece con el deseo o la instrucción que se sienta más cómodo para conversar. Usted no necesita comenzar su conversación con su ser querido con un tema difícil, como el uso de equipo y de intervenciones médicas para el mantenimiento artificial de la vida.

2. Dese tiempo para conversar acerca de sus deseos, de modo que su familia sepa cuán importante son estos para usted.

3. Asegúrese de tener copias de su directiva anticipada para entregar a las personas que usted quiere incluir en su conversación, pídale a ellos que traigan su copia al hospital en caso de que se enferme y sea necesario hospitalizarlo(a).

4. Cerciórese de discutir tus deseos e instrucciones con la persona que escogiste como tu Agente para el cuidado de la salud.

5. Al conversar con tu familia y amigos tienes una excelente oportunidad, para clarificar tus deseos en relación a los asuntos de tu cuidado médico, espiritual y emocional al final de la vida.

Quisiéramos invitar a la(s) persona(s) que usted escogió como su Agente para el cuidado de la salud, de modo que asista a la última reunión la próxima semana. Vamos a hablar de cómo ser un buen agente para el cuidado de su salud.
Sesión III

Compartir y Evaluar

“¿Para que vivimos, sino para hacer la vida de otros menos difícil?”
George Eliot (Mary Ann Evans)

Introducción

Si usted no ha expresado sus preferencias en un documento de directivas anticipadas, no podrá influir sobre las decisiones que el equipo médico y sus familiares puedan tomar en relación a su tratamiento al final de la vida, en caso de que usted no esté en capacidad de expresar sus preferencias. Cada ser humano tiene sus preferencias en relación al final de la vida y estos no pueden llevarse a cabo si la persona no los expresa. Por ejemplo; si una persona no expresa su deseo, pudiera terminar recibiendo tratamiento médico para prolongar la vida artificialmente a pesar de que su preferencia es dejar que el proceso de la muerte tome su curso. El mejor momento para completar un documento de directivas anticipadas es sin lugar antes de una crisis de su salud que amerite una intervención médica.

Si conversas con tu familia acerca de tus preferencias del cuidado médico, les evitarás un dolor a ellos en caso de que tengan que tomar decisiones sobre tu cuidado médico sin saber tus deseos e instrucciones finales. Si expresas tus deseos harás que un momento tan difícil se convierta en algo un poco más fácil de soportar porque tu familia sabrá que estarán respetando tus deseos.
¿Completó usted el documento de directivas anticipadas que recibió en nuestra última reunión?

( ) Sí  ( ) No

¿Habló con su familia acerca de sus deseos de su cuidado médico al final de la vida?

( ) Sí  ( ) No

Si habló con su familia, ¿Cómo reaccionaron ellos?

Si no habló con ellos, ¿Qué le impidió hacerlo?

Como Ser Un Buen Representante Para La Toma De Decisiones Del Cuidado Médico

Un familiar o un amigo suyo, le ha pedido que usted sea el representante legal para la toma de decisiones del cuidado médico de esa persona. Esto significa que usted puede tomar decisiones médicas en nombre de este individuo en caso de que ella o el esté incapacitado para expresar sus deseos. Al ser seleccionado como el representante legal de esta persona usted no solamente es la persona que transmite los deseos e instrucciones de este individuo, sino que esta persona probablemente lo eligió porque lo ama y confía en usted. Al seleccionarlo como su representante legal, este miembro de su familia o amigo le otorga a usted la autoridad de evaluar y realizar decisiones éticas que tienen que ver con situaciones médicas al final de la vida, en nombre de su amigo o ser querido.

Como el representante legal, es su deber velar que los deseos de esta persona sean cumplidos. Conozca los deseos de esta persona con anticipación. Hágale preguntas cuando converse con el o ella acerca del tema de los deseos del cuidado médico al final
de la vida. Si por alguna razón, usted no puede cumplir con los deseos de su representado, pídale a esa persona que escoja a otro individuo para que sirva como su representante legal para la toma de decisiones del cuidado médico.

Los médicos y las enfermeras que cuidan a su representado deben saber quien es usted y como comunicarse con usted. Hágale preguntas en relación al cuidado médico y esté seguro de que se cumplan los deseos de su representado.

Esta responsabilidad no debe tomarse livianamente. Cuando llegue el momento de involucrarse en la toma de decisiones de su representado, su tarea será: hacer preguntas, obtener respuestas satisfactorias, planificar y adaptar planes del cuidado médico con el fin de velar que se cumplan los deseos de su representado.

Que Hacer En El Lecho De La Persona Moribunda

En primer lugar, el hecho de que usted está al lado del ser querido, es lo más importante que pueda hacer. No se preocupe por tratar de buscar las palabras adecuadas que decir en este momento. Las personas moribundas en general le gustan que sus seres queridos:

1. Le tomen de la mano y le hablen aunque parezca que no responden
2. Le toquen su música favorita
3. Le lean lecturas religiosas y oren por el/ella
4. Le muestren fotografías y le recuerden de historias de personas conocidas
5. Lo mantengan al día con los eventos recientes en las noticias, la familia y la iglesia
6. Lo escuchen, a pesar de que pareciera que lo que su ser querido dice carezca de sentido
7. Le aseguren que el o ella no es una carga para usted. Dígale que siempre lo recordará.

8. No diga cosas que no son verdad, como por ejemplo decirle que la situación va a mejorar aunque usted sabe que el doctor le dijo lo contrario.

Preparación Para El Proceso De La Muerte

Desde la perspectiva cristiana, lo más importante que usted puede hacer para prepararse para el proceso de la muerte es desarrollar una relación personal con aquel que vino como un niño en Belén y aceptarlo como su salvador personal. Conocer a Jesús como su salvador personal le traerá paz y la seguridad de la vida eterna.

Otro aspecto importante que usted puede hacer para prepararse para el proceso de la muerte es desarrollar y mantener relaciones saludables con los miembros de su familia, amigos y miembros de la iglesia. Es importante resaltar que el proceso de la muerte no solamente es una experiencia de un individuo, sino es una experiencia corporativa de la comunidad. Cuando la muerte llega, la familia añora estar con el difunto. Sin embargo, el cristiano tiene la seguridad de que esta separación es algo pasajero. En el momento de la muerte, los creyentes no se lamentan como aquellos que no tienen esperanza (1 Tes 4:13). Los creyentes se consuelan en la “bienaventurada esperanza”, la esperanza de la resurrección.

Evaluación Del Seminario

Le agradecemos altamente su respuesta a las siguientes preguntas, pues nos ayudarán a evaluar el seminario y proveer datos para futuras presentaciones. La información que Ud. provea será confidencial.
1. Datos personales (escoja solamente una respuesta):

¿Qué edad tiene Usted?
( ) 60 - 65 ( ) 66 - 70 ( ) 71 - 75 ( ) 76 - 80 ( ) Más de 81

Sexo: ( ) Masculino ( ) Femenino

Estado Civil
( ) Casado ( ) Separado ( ) Divorciado ( ) Soltero ( ) Viudo

2. Por favor marque el número que mejor exprese su opinión al respecto.

Hacer planes para el cuidado al final de su vida, es parte de ser un mayordomo cristiano

1 2 3 4 5
Muy en desacuerdo En desacuerdo No estoy seguro De acuerdo Muy de acuerdo

Si estoy incapacitado(a) para tomar decisiones de mi cuidado médico, me gustaría que alguien en quien confío, pueda tomar esas decisiones por mí.

1 2 3 4 5
Muy en desacuerdo En desacuerdo No estoy seguro De acuerdo Muy de acuerdo

3. He hablado con mi familia sobre el cuidado de mi salud al final de mi vida.

( ) Si ( ) No ( ) No sé

Si has hablado con tu familia ¿Cómo evaluarías su respuesta?

1 2 3 4 5
Muy pobre Pobre Regular Buena Excelente

¿Qué te ha impedido hablar con tu familia?
4. He firmado el documento de directivas anticipadas para designar mi representante legal para la toma de decisiones sobre el cuidado de mi salud. (Marque una respuesta)
   ( ) Sí    ( ) No    ( ) No sé

5. Ha preparado el documento de directivas anticipadas de instrucciones sobre el cuidado de su salud (Marque una respuesta)
   ( ) Sí    ( ) No    ( ) No sé

6. ¿Cómo usted evaluaría en general la efectividad de este seminario?
   
   [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5  
   Muy pobre   Pobre   Regular   Bueno   Excelente

7. Estoy agradecido de haber asistido a este seminario por la siguiente razón (o razones).

8. No estoy agradecido de haber asistido a este seminario por la siguiente razón (o razones).

9. ¿Qué sugerencias nos puede dar para mejorar la realización de futuros seminarios como éste?
APPENDIX B
PRE-TEST AND POST-TEST SURVEYS

PRE - TEST

The response to the following questions is appreciated. Your answers will assist to evaluate the seminar and to provide data for further programs. Your information will be kept confidential.

1. Personal Data (Circle only one)
   - How old are you?
     ( ) 60 – 65  ( ) 66-70  ( ) 71 – 75  ( ) 76-80  ( ) More than 81
   - Are you
     ( ) Male  ( ) Female
   - Are you currently
     ( ) Married  ( ) Separated  ( ) Divorced  ( ) Single  ( ) Widowed

2. Please circle the number that best expresses your opinion.
   - Making plans for end-of-life care is part of being a Christian steward
     1  2  3  4  5
     Strongly Disagree  Not sure  Agree  Strongly Agree
   - If I am not able to make my own health care decisions, I would like to have someone I trust to make those decisions for me
     1  2  3  4  5
     Strongly Disagree  Not sure  Agree  Strongly Agree
3. I have expressed my end-of-life care wishes to my loved ones or someone I trust.
   (Circle your answer)
   ( ) Yes  ( ) No  ( ) I don’t know

4. Have you signed a Health Care Agent (Power of Attorney for Health Care) advance directive document? (Circle your answer)
   ( ) Yes  ( ) No  ( ) I don’t know

5. Have you completed the Instructions for Health Care (Living Will) advance directive document? (Circle your answer)
   ( ) Yes  ( ) No  ( ) I don’t know

PRE-TEST / SPANISH

Le agradecemos altamente su respuesta a las siguientes preguntas, pues nos ayudarán a evaluar el seminario y proveer datos para futuras presentaciones. La información que Ud. provea será confidencial.

1. Datos personales (escoja sólo una respuesta):
   - ¿Qué edad tiene Usted?
     ( ) 60 - 65  ( ) 66-70  ( ) 71 - 75  ( ) 76-80  ( ) Más de 81
   - Sexo: ( ) Masculino  ( ) Femenino
   - Estado Civil
     ( ) Casado  ( ) Separado  ( ) Divorciado  ( ) Soltero  ( ) Viudo
2. Por favor marque el número que mejor exprese su opinión al respecto.

- Hacer planes para el cuidado al final de su vida, es parte de ser un mayordomo cristiano

1 2 3 4 5
Muy en desacuerdo En desacuerdo No estoy seguro De acuerdo Muy de acuerdo

- Si estoy incapacido para tomar decisiones de mi cuidado médico, me gustaría que alguien en quien confío, pueda tomar esas decisiones por mí.

1 2 3 4 5
Muy en desacuerdo En desacuerdo No estoy seguro De acuerdo Muy de acuerdo

3. He expresado mis deseos sobre cuidado de mi salud al final de mi vida a mis seres queridos o alguien en quien confío.

( ) Si ( ) No ( ) No sé

4. ¿Ha firmado el documento de directivas anticipadas para designar su representante legal para la toma de decisiones sobre el cuidado de su salud? (Marque una respuesta)

( ) Si ( ) No ( ) No sé

5. ¿Ha preparado el documento de directivas anticipadas de instrucciones sobre el cuidado de su salud? (Marque una respuesta)

( ) Si ( ) No ( ) No sé

POST-TEST

Response to the following questions is appreciated. Your evaluation will assist us in future seminars. Your information will be kept confidential.
1. Personal Data (Circle only one)
   - How old are you?
     ( ) 60–65 ( ) 66-70 ( ) 71–75 ( ) 76-80 ( ) More than 81
   - Are you: ( ) Male ( ) Female
   - Are you currently
     ( ) Married ( ) Separated ( ) Divorced ( ) Single ( ) Widowed

2. Please circle the number that best expresses your opinion.
   - Making plans for end-of-life care is part of being a Christian steward.
     1  2  3  4  5
     Strongly Disagree Not sure Agree Strongly Agree
   - If I am not able to make my own health-care decisions, I would like to have
     someone I trust to make those decisions for me
     1  2  3  4  5
     Strongly Disagree Not sure Agree Strongly Agree

3. Did you talk to your family about end-of-life issues?
   ( ) Yes ( ) No
   - If yes, how would you rate their response?
     1  2  3  4  5
     Very Poor Poor Fair Good Excellent
   - If no, what hindered you?

4. Have you signed an agent for health-care (power of attorney for health-care)
   advance directive document? (Circle your answer)
   ( ) Yes ( ) No ( ) I don't know
5. Have you completed the instructions for health-care (Living Will) advance directive document? (Circle your answer)

( ) Yes ( ) No ( ) I don’t know

6. How would you rate the overall effectiveness of the seminar?

1 Very Poor 2 Fair 3 Good 4 Excellent 5 Poor

7. Please answer one of the following statements:

- I am glad that I came to this seminar because

- I am not sure I am glad I came to this seminar because

8. What suggestions do you have for improvement of future seminars?

POST-TEST / SPANISH

Le agradecemos altamente su respuesta a las siguientes preguntas, pues nos ayudarán a evaluar el seminario y proveer datos para futuras presentaciones. La información que Ud. provea será confidencial.

1. Datos personales (escoja solamente una respuesta):

¿Qué edad tiene Usted?

( ) 60 – 65 ( ) 66-70 ( ) 71 – 75 ( ) 76-80 ( ) Más de 81

Sexo: ( ) Masculino ( ) Femenino

Estado Civil

( ) Casado ( ) Separado ( ) Divorciado ( ) Soltero ( ) Viudo
2. Por favor marque el número que mejor exprese su opinión al respecto.

Hacer planes para el cuidado al final de su vida, es parte de ser un mayordomo cristiano

1  2  3  4  5
Muy en desacuerdo En desacuerdo No estoy seguro De acuerdo Muy de acuerdo

3. Si estoy incapacitado(a) para tomar decisiones de mi cuidado médico, me gustaría que alguien en quien confío, pueda tomar esas decisiones por mí.

1  2  3  4  5
Muy en desacuerdo En desacuerdo No estoy seguro De acuerdo Muy de acuerdo

4. He expresado mis deseos sobre el cuidado de mi salud al final de mi vida a mis familiares.

( ) Si ( ) No ( ) No sé

Si has hablado con tu familia ¿Cómo evaluarías su respuesta?

1  2  3  4  5
Muy pobre Pobre Regular Buena Excelente

¿Qué te ha impedido hablar con tu familia?

4. He firmado el documento de directivas anticipadas para designar mi representante legal para la toma de decisiones sobre el cuidado de mi salud.

(Marque una respuesta)

( ) Si ( ) No ( ) No sé
5. Ha preparado el documento de directivas anticipadas de instrucciones sobre el cuidado de su salud (Marque una respuesta)

( ) Si   ( ) No   ( ) No sé

6. ¿Cómo usted evaluaría en general la efectividad de este seminario?

1  2  3  4  5
Muy pobre  Pobre  Regular  Bueno  Excelente

7. Estoy agradecido de haber asistido a este seminario por la siguiente razón (razones).

8. No estoy agradecido de haber asistido a este seminario por la siguiente razón (o razones).

9. ¿Qué sugerencias nos puede dar para mejorar la realización de futuros seminarios como éste?
BIBLIOGRAPHY


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