A guidebook for pastoral care in light of today's medical and legal choices

Abiding Presence:

Living Faithfully in End of Life Decisions

For medical personnel, caregivers, pastors, deacons and other providers of end-of-life treatment, care and support.

The Presbyterian Church (U.S.A.)
2016

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THE REVEREND DR. J. HERBERT NELSON, II
STATED CLERK OF THE GENERAL ASSEMBLY

Dear members and friends of the Presbyterian Church, and particularly those facing end-of-life decisions:

"In life and in death, God is with us," says the Brief Statement of Faith. When I was in the pastorate, I was regularly at the hospital bedside as death approached. Sometimes the choices are clear, and we pray to respond in confidence and love to fear and pain. But sometimes the new choices presented by the doctors are more complicated. We have more treatment options to consider, some of which may hasten death, and each option can bring its own stress. This pastoral resource is meant to help in both clear and complicated circumstances, so that we may have a steady sense of God's abiding presence in either case.

I write this brief preface to those both within and outside our church in my capacity as Stated Clerk of the General Assembly, the highest policy making body of our denomination, to confirm that this study, **Abiding Presence: Living Faithfully in End-of-Life Decisions,** was approved by the 222nd General Assembly of the Presbyterian Church (U.S.A.) on June 23, 2016 in Portland, Oregon. The study team of doctors, nurses, ethicists, pastors, and a hospice director appointed by the Advisory Committee on Social Witness Policy determined that our church most needed a caring and careful handbook on end-of-life choices, for both professional and volunteer care-givers. As the end there is a resolution that addresses public policy questions, such as "aid in dying" legislation and the inclusion of counseling in health insurance plans. I commend this study, then, as Reformed theology and ethics applied to practical questions that face us all.

The General Assembly adopts studies and statements on matters of Christian conscience under the guidance of the Holy Spirit and in exercise of its responsibility to witness to the love and justice of Jesus Christ in every dimension of life. Without minimizing the strong General Assembly positions in favor of healthcare for all, this statement focuses on informing and empowering care-givers and all of us when we face death. The recommendations in the resolution direct ministries and advocacy by the units and staff of the General Assembly agencies, but are advisory to all others— these matters can be quite personal. I urge you to use both the pastoral guide and the resolution in sermons, adult education, and deacon training to prepare people to be wise Christians in hospital and hospice situations.

Many of us may be unsure of what we think or feel until we face a given matter, and we may also be unfamiliar with what the church has taught, or how previous teachings apply to new treatments. If some of this uncertainty and even testing is part of your experience, we pray that you may be helped by this handbook.

Yours in Christ's service,

J. Herbert Nelson, II

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Stated Clerk of the General Assembly
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Approved by the 222nd General Assembly (2016)

Presbyterian Church (U.S.A.)

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The committee wishes to thank Dr. Elliot Wicks for his layout suggestions for this final report format.

Note: The information in this booklet is not intended to constitute legal advice and should not be relied upon in lieu of consultation with appropriate legal advisors in your own state and jurisdiction.

Introduction

"I'm convinced that nothing can separate us from God's love in Christ Jesus our Lord: not death or life, not angels or rulers, not present things or future things, not powers or height or depth, or any other thing that is created."[1]

How do I want the end of my life to be? As Christians we know that our dying, just as our living, is within the providence and care of God.[2] We do not have a choice in the God-given certainty of our deaths, but we do have choices about how we face that reality and plan for that transition. How do we best claim and practice the presence of Christ and the hope of resurrection at the end of life? There will be many different answers to that question, as we are called to many different roles and responsibilities in life and therefore hold many different aspirations and expectations for our lives. In turn, at the end of our lives, we have many different aspirations and expectations for our dying. If we are to be responsible to our beliefs, our hopes, and our aspirations, we must think about our goals for medical care and treatment as our lives draw to a close. This is not simply a matter of expressing our freedom as Christians before God. Advance care planning is also a gift we can give to our families and others entrusted with our care who need to know what kinds of care will be meaningful and fulfilling to us.

Advance care planning involves conversations that are not always simple or comfortable. After all, those conversations force us to confront our own mortality, something that for different people can range from difficult to deeply existentially disturbing. Such end-of-life conversations therefore require an environment of trust, support, and careful listening. Pastoral care offers an environment that can and should invite and affirm conversations about end-of-life care and its goals and limits. Similarly, congregational life can provide an environment where education and conversation about end-of-life goals and concerns can help provide greater clarity about both personal values and shared faith commitments.

In the context of a community of faith shaped by the Reformed tradition, these conversations will be influenced by a distinctive set of "lenses" or ways of seeing and understanding both life and death. Some of our central convictions include: (1) that all life is a gift of God, (2) that life is best lived as a covenantal relationship between God, ourselves, and others, (3) that life is lived most fully in response to a sense of divine calling, and (4) that God's presence and power are not limited by the boundaries between life and death. These significantly affect how we talk about the end of life in at least two ways. First, these convictions provide a context of faith and hope in which we can begin to understand our own mortality neither as a defeat nor as a meaningless event, but instead as surrounded and inhabited by the loving presence of God. In this way, we can avoid despair and be empowered toward honesty and clarity. Second, these convictions can guide us through the increasingly complex choices our medical technologies now allow us to make. Seen in relation to God, our deaths are neither an end to be embraced nor a crushing enemy to be resisted at all costs. Instead, they are a part of the ordering of God's good world to which we are called and enabled to respond with imagination, love, and openness to God's grace.

Conversations about advance care planning should never be forced. However, sometimes care-recipients, their families, and caregivers all need encouragement and assistance as they give voice to their convictions and concerns and gain clarity about the variety of choices they face. It is important to recognize that each partner in the conversation brings values, principles, beliefs, and virtues to the challenge of advance care planning. Healthcare professionals, spiritual care providers, family members, and patients all have spiritual convictions, conscientious concerns, and ethical standards. Each of these participants also function within institutions and professional communities that seek to foster cultures of compassion, commitments to caring, and the development of professionalism. At its best, advance care planning enables these interested parties to give voice to their religious and moral concerns so that they can be heard and understood.

I. Contexts for Advance Care Planning and End-of-Life Care

When advance care planning is done well, it is a tremendous benefit to patients, families, and healthcare professionals. It allows people approaching the end of life to shape the care they will receive by making their wishes and needs known. It also provides family and friends entrusted with decision-making responsibilities the comfort of knowing the wishes of their loved one. Finally, it insures that healthcare professionals are well informed about their patients' choices.

While these conversations are difficult, it appears that a large majority of Americans want to have discussions about end-of-life options with their doctors. What is troubling, however, is that few seriously ill patients get to have these conversations. The desire to correct this disparity is largely responsible for the growing attention to advance care planning. But initiating end-of-life conversations is only a beginning. The quality of advance care planning depends on having conversations that explore preferences and values in depth and that occur not just once, but numerous times throughout the progression of a person's health care. Not only are such conversations too rare, they also often occur too late to have optimal benefit. What is more, health professionals themselves express reservations about how well prepared they are to initiate and facilitate these crucial conversations. This concern suggests the need for better training in medical and allied health education, and highlights the importance of empowering patients to participate meaningfully in end-of-life conversations.

The idiosyncratic and variable nature of advance care conversations are a central concern for a church that espouses a continuum of compassionate, covenantal care, as reflected in actions by several past Presbyterian General Assemblies (See Appendix A). To reckon with the barriers and gaps that are detrimental to compassionate end-of-life care, the church needs to understand several overlapping and interrelated contexts that affect and surround advance care planning. This understanding requires consideration of a number of contexts in which advance care planning unfolds. The clinical/medical

context is the setting in which advance care planning would be expected to take place, but often does not. The theological/ethical context is the constellation of beliefs, convictions, principles, and virtues that care recipients, care providers, and their supporting communities bring to advance care planning. These contexts set the stage for advance care planning as a challenge and a possibility, as do the historical/legal context and such social and cultural factors as economic class, ethnicity, and gender. After elaborating this multidimensional background, the role of pastoral and congregational life can be clearly articulated.

The Clinical Context

In the context of clinical medicine, we are faced with fragmentation and lack of integration. In the words of Dr. Philip A. Pizzo, co-chair of the Institute of Medicine Committee on Approaching Death, "Unfortunately, as a nation we do a disappointingly poor job of delivering seamless, compassionate care that honors the individual preferences of those nearing the end of life. This happens mainly because we do not know or uphold what our patients want or desire and neglect to listen or take the time to convey information completely and accurately."[3] The Institute of Medicine recommends that care of those with advanced serious illness "should be seamless, high-quality, integrated, patient- and family-centric, and consistently available."[4] This excellent summary describes what advance care planning should seek to achieve and highlights areas in which the church can contribute to the improvement of end-of-life conversations.

Consider these consequences of today's complex and often-fragmented clinical setting. Several specialists may see a hospital patient and the admitting physician may have little contact with the patient. Managing a patient's care in the hospital is often the responsibility of a hospitalist – a physician employed by a hospital to provide care for patients during their hospital admission. This physician may be on a twelve-hour shift, with the care then assumed by another hospitalist. Further fragmentation occurs because of discontinuity between specialties such as oncology, infectious disease, pulmonology,

cardiology, and others. The primary care physician who treated the patient outside the hospital often has no contact with him or her until after they are discharged. Given the way in which various physicians each see the patient for different issues at different times, who decides that a conversation about advance care planning involving end-of-life issues is needed? The result is that often no single physician is responsible for end-of-life choices. Exacerbating the problem is the pace of life in hospitals that allows little or no time for heart-to-heart conversations, making it an easy task to delay or ignore for any given individual provider.

Healthcare professionals complain that medical and nursing education traditionally has given inadequate attention to the care of the dying, and to palliative care in particular. This leaves care providers unprepared to facilitate conversations about advance care planning. It is encouraging that the last decade has seen palliative care emerge as a new professional specialty that includes board-certified physicians and nurses as well as social workers, clergy, and other professionals. In addition, medical schools are now including these topics in the education and training of their students. However, Katy Butler has called palliative care "medicine's tin-cup specialty."[5] Inadequate numbers of palliative care specialists coupled with inadequate insurance reimbursement, result in under-utilization of the specialists best prepared to engage in advance care planning and, later, may also result in the under-treatment of pain and suffering at the end of life.

Hospice care faces its own institutional hazards when it is forced to function as the advance care plan option of last resort. Even in the medical community, there are misconceptions about whether hospice patients can continue to receive treatment for certain conditions (which they can if the goal is to improve or sustain quality of life). Some patients, for example, value in-home hospice care as a way to stay out of the hospital but are denied that comfort when conversations about their end of life are delayed. Insurance carriers and HMOs may value hospice services mainly as a way to keep patients out of hospitals, and for those not covered by Medicare there is insufficient funding for universal access to the most comprehensive forms of hospice care. Disparities in access to hospice also emerge as a function of Medicaid and Medicare

reimbursement structures. These have remained the same since the mid-80s, resulting in few hospice programs that are directed toward indigent patients, particularly those with AIDS and others who require more complex and costly care.

The failure of clinical providers to initiate conversations, or problematic delays in doing so, sometimes occur because of reluctance to broach the possibility of hospice. This may be because they continue to think they can beat the odds with yet another experimental treatment. Other times, providers avoid or soften a dire prognosis out of a fear that the patient will give up hope (an issue for some, but certainly not the majority of patients). For example, one study of cancer patients found that "physicians favored providing an apparently knowingly inaccurate survival estimate for 40.3% of patients and favored providing no survival estimate for 22.7% of patients."[6] Even when disclosed, the hesitancy of providers may result in disclosure of diagnosis that is not straightforward and therefore not fully understood. As a result, multiple studies have found that significant proportions of patients with incurable cancer do not understand the terminal nature of their condition. Furthermore, oncologists may disclose that a possible treatment is unlikely to be curative, but they often do not attend to the patient's understanding of this communication. They also present alternatives to aggressive treatment in fewer than half of their encounters with patients. Despite reported concerns about patient reactions, where open and sensitive conversations do occur, studies show that the incidence of depression is not increased. Furthermore, offering choices for palliative care can lead to an improved quality of life and greater longevity.

If the hectic pace and the plurality of caregivers hinder in-depth discussions about end-of-life issues within hospitals, what of office visits with one's physician? In the outpatient setting, physicians feel pressed to see more patients because of the lower reimbursement levels of Medicaid, Medicare, and private health insurance companies. In the face of increasing demands by insurers to document greater amounts of information in an electronic medical record, many physicians report having less time to engage in probing conversations with patients than before. For their part, patients may feel vulnerable or intimidated by fears of a possible dire prognosis

and therefore may not ask for more information about a serious diagnosis or assert their desires to engage in advance care planning. They also may not be accompanied by a loved one or other advocate who will raise such questions or insist on direct answers. Where the clinical context makes it easier to focus on an immediate symptom or ailment, both the doctor and the patient may fail to probe more deeply about long-term prospects and options.

Technological innovation has recently been making possible the virtual office visit and even the virtual hospital visit. The office visit by electronic device removes distance and long waits as deterrents to doctor-patient contact, and the digitally empowered patient can even gain access to blood tests, medical scans, and parts of physical examinations from afar instead of in a hospital. Such emerging innovations may make for easier access to healthcare providers and information for the technologically adept; however, many persons will require opportunities for in-depth conversation face-to-face with their doctors to address the range of end-of-life options and care.

Lack of reimbursement for having advance planning conversations also has been cited as a significant deterrent. Initially proposed features of the Affordable Care Act sought to address this problem, only to trigger outcries that so-called "death panels" would become a means of rationing expensive health care and "getting rid of Granny." As a result, the final version of the Affordable Care Act carried no such provision for reimbursement. This is particularly unfortunate since studies have shown that such sessions lower stress in patients and families and affect treatment choices, such as limiting hospitalizations. Even without financial incentives, some doctors have faithfully continued to initiate such conversations without charge or squeezed them into regular office visits; but reimbursements would increase the ability of providers to work these conversations into their tight schedules.

Despite the attacks that plagued the debates about the ACA, the desire to implement reimbursement for advance care planning conversations has persisted. The American Medical Association endorsed such reimbursements, and some states, including Colorado and Oregon, began covering sessions for Medicaid recipients. In July of 2015, Medicare announced plans

to reimburse doctors for conversations with patients about whether and how they would want to be kept alive if they become unable to speak for themselves. This took effect in January of 2016. The plan allows doctors, as well as qualified professionals such as nurse practitioners and physician assistants, to be reimbursed for advance care planning in face-to-face meetings with patients and any family member or caregiver that the patient wants to include. It is noteworthy that the plan sets no limit on the number of these conversations that can be reimbursed, which should encourage providers to revisit those conversations periodically. Because Medicare often sets standards for private insurers, some have already begun covering advance planning discussions, and more will likely do so with the adoption of the new Medicare rules.

While reimbursement for end-of-life discussions represents one important step in improving advance care planning, allegations that these conversations will be used to nudge people toward foregoing treatment and hastening death are likely to persist. Further, it will not guarantee participation by people who are uninsured or by patients in poverty or from racial/ethnic groups with higher levels of distrust in the medical establishment because of historical events (such as the Tuskegee Syphilis Study) or their personal experiences of unequal access and discriminatory treatment within the healthcare system. It also does not assure that healthcare professionals will be well prepared to hold these discussions or that patients and families will be prepared to make the most of them.

A recent effort to address the readiness of healthcare professionals for this challenge involves the creation of variety of "decision aids" now being publicized and analyzed in professional journals. These aids aim to provide health professionals with a structured approach to informing patients about care options and prompting them to document and communicate their preferences. However, some fear that such aids could amount to no more than a checklist to be filled out and submitted for reimbursement rather than tools that assist a robust conversation. So far these aids have remained proprietary and not publicly available. They also tend to be disease specific. As they develop and proliferate, it will be important to evaluate the ways in which these clinical tools

affect end-of-life conversations, including theological and spiritual concerns.

Advance directives, which until recently included only Living Wills and the Durable Power of Attorney for Health Care, have been perhaps the most important effort in past years at furthering advance care planning. In addition to those two foundational documents, more recent legal documents have emerged including, Physician Orders for Life-Sustaining Treatment (POLST), Medical Orders for Scope of Treatment (MOST), and Clinical Orders for Life-Sustaining Treatment (COLST). Exploring the nature of these directives and the ways they have emerged from and shaped end-of-life planning requires understanding of the historical and legal context of advance care planning.

Historical/Legal Context

Beginning in the late sixties, the popular "patients' rights" movement emerged on the heels of major medical advances in organ transplant, dialysis, resuscitation modalities, and other life-prolonging technologies. This movement elevated the notion of patient autonomy or self-determination in contrast to the traditional deference paid to the authority and judgment of medical professionals. Court decisions in so-called "right to die" cases such as those involving Karen Ann Quinlan and Nancy Cruzan (see Appendix B) established a right to refuse treatment by persons in a persistent vegetative state or their surrogates. Additionally, a pivotal consideration in the Cruzan case centered on the need for "clear and convincing evidence" that the patient would not want to remain on life support under such circumstances. Either written statements or oral statements made to family members, friends, or co-workers while the patient was still conscious and competent were considered essential by some state courts.

The Supreme Court's Cruzan decision of 1990 affirmed the freedom of all persons to judge for themselves the benefits and burdens of accepting further life-prolonging treatments, or even the perceived burden of medical extension of life itself. In turn, the Court affirmed the right of patients to accept or reject

medical interventions on that basis. For persons no longer capable of forming these judgments, the Court also allowed the states to require significant levels of evidence regarding the judgments those persons had made while competent. Recognizing both of these aspects of the High Court's ruling, the U.S. Congress acted within months to encourage and enable competent adults to express prospectively their treatment decision preferences before the onset of terminal illness or incompetence. That legislation, known as the Patient Self-Determination Act or PSDA (1990), created a legal obligation for healthcare institutions receiving federal funding to educate and assist their patients, clients, residents, staff and communities regarding the creation of advance directives for health care (e.g., Living Wills and Durable Powers of Attorney for Health Care) in accordance with each state's laws. These documents not only allow individuals to express their own considered preferences regarding treatment options or proxy decision-makers, but they also provide the equivalent of "clear and convincing evidence" of the individuals' wishes if and when they become incapable of expressing them.

In contemporary U.S. culture, public policy and majority public opinion are essentially in agreement with respect to the freedom of individuals to refuse medical treatment, even when it is life-prolonging. However, there is still significant disagreement about whether artificial feeding and hydration constitute "treatment," and thus, whether they legitimately can be refused. Additionally, while the Supreme Court has clearly affirmed one's right to refuse life-prolonging treatment, it has not ruled in favor of any right to *assistance* in bringing about one's death. The Court did, however, allow states the freedom to permit and regulate such assistance. As of 2015, five states currently allow "physician aid in dying" (PAD), with more than half of other state legislatures considering bills that would permit it. These typically allow for physicians, under certain stringent conditions, to prescribe lethal doses of medications that can be taken by patients, if the patients so choose. In contrast, "active euthanasia," refers to a situation in which a physician or other person acts directly to cause the death of a suffering person, for example by directly administering a lethal dose of medication. This remains illegal throughout the United States, though it has been legalized in several European countries, in some instances even for persons who are not

terminally ill. Our American societal context at present is one in which a growing percentage of Americans support "physician aid in dying," but currently one must move to one of the five permitting states to receive such assistance legally.

The implementation of the Patient Self-Determination Act (1990) has involved a concerted effort by many hospitals to get all patients to complete advance directives. Despite these efforts, it is estimated that only about 20 percent of the populace has done so. In fact, fewer than 50% of severely or terminally ill patients have an advance directive in their medical records.[7] Among patients who did have advance directives, their physicians were unaware of it at least 65% of the time and very few patients with advance directives had received input from their physicians before writing their advance directives, highlighting the dearth of end-of-life conversations in the clinical context. Lack of explicit end-of-life planning leaves surrogate decision makers in a difficult position and, as a result, it is estimated that surrogate decision makers are accurate only about 68% of the time when they try to predict patient preferences for end-of-life care.[8] These problems are compounded for persons who have been marginalized by lack of access to the healthcare system or by discriminatory treatment within it, who are less likely to have advance directives and more likely to insist on all-out efforts to lengthen their lives when they are terminally ill. Even for those who have advance directives, there is no guarantee these will be discovered and honored in critical situations. All of these problems highlight the importance of the church's role in promoting advance care planning, which, in order to be successful, needs to be a community effort undertaken among patients, providers, congregants, and others.

The latest development in advance directives is the state-legislated Physician Orders for Life-Sustaining Treatment (POLST). Like living wills these documents allow patients to express their choices about various types of life-sustaining treatment. Unlike Living Wills, however, POLST forms are also signed by the patient's physician and constitute validated physician orders. (See a state-by-state review of these variously named orders in the appendix.) These forms contain a detailed checklist of conditions requiring a decision about oral antibiotics, intravenous feeding, feeding tubes, etc. If a section

is not filled out, full treatment is to be administered. Moreover, these forms are made part of a patient's medical record and are to be reviewed at least annually. POLST forms, if used in the context of well-conducted in-depth conversations, can offer a promising opportunity for better advance care planning. However there are many considerations and conversations that need to occur before the specific issues outlined on POLST forms are decided.

Still another setting where meaningful conversations about end-of-life choices might occur is in nursing homes and other long-term care settings. The residents of these facilities tend to be at stages of the life course or in a particular disease progression that warrant advance care planning. However, there are barriers to effective discussions in these contexts. Many nursing homes are understaffed, and poorly paid aides with minimal training and rapid turnover render most of the care. Complicating the situation, a majority of residents suffer from dementia, seldom receive visits, and commonly experience a regimen that is short on attention to individual needs and preferences and long on impersonal management. Some doctors report that nursing home residents who are wards of the state seldom get Do Not Resuscitate orders. State-appointed guardians are loath to reject treatment, so their wards sometimes receive rather aggressive treatment (e.g. the surgical insertion of feeding and/or breathing tubes), even when it is not medically beneficial or is overly burdensome. Stronger advocacy for palliative care could be helpful in such circumstances.

Examination of the clinical context of advance care planning reveals that clinical encounters, particularly those involving end-of-life planning or care, do not involve doctors and patients alone. Rather, they are variously embedded within family systems, teams of other healthcare professionals, hospital and governmental regulations, insurance company rules, quality control mechanisms, ethics committees, and many other components of the modern medical enterprise. Treatment decisions also may be complicated by differences in culture, minority status, limited or absent financial resources, or the perception of discrimination.

Theological/Ethical Context

Advanced care planning is contextualized by a number of theological, spiritual, and ethical issues. Each participant brings his or her spiritual and moral convictions to the challenges of end-of-life planning and care. This planning process includes members of a patient's broader congregation and community that could and should assist with the responsibilities of caring for the dying. Not only do doctors, nurses, social workers, chaplains, hospice staff members, therapists, pastors, Stephen Ministers, family members, and patients have spiritual convictions, conscientious concerns, and ethical standards, but they all live and act from within various institutions, communities, and professional roles. In the context of the hospital, clinical ethicists, ethics committees, and chaplains all facilitate conversations about values and principles that are shared as well as those that may be in conflict. These professionals, in particular, will engage with a patient's religious and spiritual values. For its part, the Church needs to facilitate clarity, among congregants, about their personal values, beliefs, and expectations of dying. The preparation of advance care planning, including assistance within the Church, will represent an indispensable resource to congregants as they encounter the milieu of healthcare providers to whom they need to articulate their end-of-life wishes. The question becomes: In what ways should the Church facilitate advance care planning for persons of faith?

Christian faith and practice should not be regarded as a compendium of religious beliefs and principles to be imposed from above onto end-of-life care. Instead, the Christian faith represents a set of spiritual and moral resources that exert a discernible influence in the societal, institutional, and clinical settings in which decisions are made and care is given and received. That is, the spiritual and moral perspectives of Christianity should offer something distinct to the end-of-life conversations between a person of faith, their families, physicians, and others. As such, churches have a great opportunity and responsibility in their pastoral and educational ministries to equip both patients and healthcare providers and recipients for their roles in advance care planning.

The resources of the Reformed tradition for equipping these various participants are quite rich. For example, our tradition places a great deal of emphasis on the human capacity to make choices, which has obvious accord with the emphasis upon patient autonomy in end-of-life decision making that governs so much of medical practice today. But there also is something distinct offered by the Reformed theological perspective, particularly where it conceives of human decision making as always taking place within the larger context of perceptions, beliefs, and feelings about what is ultimately true and good—about what, or who, should be worshiped. All decisions are made, however implicitly, with reference to God. What we believe about God has a profound impact on how we understand our own life and death and on how we should navigate them. Although the Reformed tradition does not always speak with one voice on these questions, there are key affirmations that should be taken as "points to consider" when we have conversations about these topics.

First, God is "sovereign." This means that God is a power and presence that is not diminished by any event in life or in death. In life and death we belong to God! "Sovereignty" need not mean control, but it does mean *persistence*: God is always at work in everything that happens, imposing limits on us, but also creating possibilities for us. Thus, while the Reformed tradition has an affinity with contemporary notions of patient autonomy, it distinctly adds the perspective that when we decide what to do, we are not acting on our own in a universe without meaning. Rather, we decide what we believe God is "enabling and requiring" us to do and to be.[9]

Second, God both blesses and orders (or "governs"). The first creation story in Genesis 1 is punctuated by the theme of "blessing." God sees that the creation is good and then pronounces a blessing on all creatures, effectively empowering them to continue the creative work that God has begun. The power of God's blessing is seen in the resilience of life and in its persistent capacity to renew itself, to heal, and to transform. Life goes on in the power of this blessing and to participate in it is joy.

But the blessing is not given without limits. God also orders—or, in older language, "governs." God places creatures in larger contexts in which we have to contend with powers that are greater than ourselves. Death is one feature of this context. In death, it is not so much that we experience the natural destiny of our bodies, nor that we undergo a curse as the penalty for our sin. The Reformed perspective supports neither a moralistic nor a vitalistic view of life.[10] Rather, death entails being subject to powers that are beyond us. In the world that God orders, each of us has his or her ultimate limit. Although we often experience frustration, pain, and grief when we encounter it—in part because we are reluctant to accept our limits and in part because we find the permanent loss of relationships that death entails to be nearly intolerable—there is nothing wrong or broken about this ultimate boundary.

Third, God orders or governs life in part by means of "covenantal" relationships. From the beginning, God is seen in Scripture as a God of love, a God of relationships. God established and sustains a relationship with human beings as "covenant-partners,"[11] granting us the capacity to make choices in response to the grace that always precedes, follows, and surrounds all of life. Human response to grace is shaped by senses of gratitude and responsibility. It is in this context that we discover the joy of what our tradition calls "vocation." We are thankful for the gifts that are given to us, and we seek to show our gratitude by responsibly caring for them and using them for the benefit of God's wider purposes in the world.

Part of what it means to live in covenant is to be responsive not only to God, but also to others who may be affected by our actions. Because life is fulfilled in relationship with others, judgments about the present "quality of life" can be seen as assessments of the capacity for sustaining and enjoying relationships. Notions of quality of life are central to end-of-life planning and at the heart of contemporary bioethics. What a Reformed perspective distinctly adds is the perspective that our lives are never only in our own hands, but their meaning is shared in communities; and so in extreme circumstances we can ask, "What are the enduring possibilities for meaningful relationship left to my life?" "How does my life benefit, support, and bless others who may in some way depend on

me?" We might even ask questions that have not so much to do with the quality of one's own life but with the effects that the continuation or ending of one's life might have on others. When our lives are seen as part of a wider fabric of relationships before God, such questions multiply and decision making can become even more complex. Nonetheless, these kinds of questions can help orient end-of-life decisions in terms of vocation. We can come to see the end of life as a calling to which we must respond faithfully and can even find some measure of fulfillment in doing so.

These convictions in general support many of the norms implicit in medical practice, such as the duty not to harm and the duty to do what benefits the patient and advances his or her good, and gives those norms a particular emphasis.[12] Good, for example, is understood relationally, in terms of our created capacity for relationships and of our vocational responsibility for them. These same norms also guide patient decision making. For example, we have an obligation to avoid harm (to ourselves and our loved ones). In the Reformed tradition, suffering has no value in itself. It may be accepted when inevitable, and it may be endured with faithfulness, but suffering itself does not confer merit or uniquely carry any spiritual benefits. We can ask ourselves, therefore, whether enduring pointless suffering does not amount to the infliction of unnecessary harm on ourselves.

Of course, this principle also applies to the sustenance of life. The obligation to do no harm should give us serious pause when contemplating ending medical treatments or requesting treatments that would hasten our deaths. In both cases, however, the obligation to do no harm must be balanced against the obligation to promote the good. Again, where good is defined relationally, as in the context of the Reformed tradition, decision making becomes less focused on narrow considerations about the morality of specific acts or interventions, expanding instead to include a broader set of people and circumstances. Sharing a vision of God's ordering of human life in relation to others, we may view death as being subject to forces in God's world that we do not control. These forces are not limited to injury and disease but also include pain and suffering. When these are overwhelming, and when they destroy the capacity for human relationships and steal the

joy from living, we may reasonably conclude that God is be calling us to face our limitations and to accept the inevitability of death. However, it is also true that individuals with very limited capacity to respond to others may still possess sufficient capacity to be in relationship with those they love and trust. Ultimately these decisions rest with particular individuals and emerge from their various conversations, but the theological context offered by the Reformed tradition provides a distinct and important frame for persons of faith who are struggling with these issues.

II. Pastoral Support for End-of-life Care and Choices

Pastors and others taking pastoral leadership in a congregation (e.g., commissioned ruling elders) know that they have an important role to play in helping their parishioners with end-of-life decisions. However, they are often uncertain how to engage persons in these discussions and feel ill-suited to engage other professionals in the healthcare environment. These issues will be explored around two key questions:

1) *What can I do to help persons in my congregation with end-of-life issues?* And
2) *How can I, in my pastoral role, fit in to the healthcare setting?*

The first question takes on greater urgency with the proliferation of life-sustaining medical technologies. Most patients can justify even substantial amounts of pain and suffering if a cure is a potential outcome. But many times the burden of a disease or its treatment exceeds the potential benefit to the patient. This can be true of certain cancers, for example, as well as progressive diseases such as advanced dementia, chronic heart failure and progressive lung disease. In light of these challenges, the first important question delineated above can be elaborated to ask: *What does it mean to live faithfully and die well, and how can I contribute to this task as a spiritual leader?* There are several critical considerations:

1. All persons are beloved by God, and wholeness is found in our relationship with both God and the communities around us. A person is more than a body, and diseases, therefore, should not eclipse one's broader identity as nested in one's relationships with others and with God. Disease and disability may reduce our capacity to function in certain ways, but they should not be allowed to define us. In fact, even our mortality itself does not define us.

   The apostle Paul reminds us that God's strength is displayed in and through our weakness. Pastoral leaders should advocate for equal treatment of persons

without discrimination based on limitations or disabilities because we become whole by God's grace in spite of whatever diseases or disabilities we have.

2. So if God's grace sustains us, why think about death at all? Forethought is needed because in our technologically advanced society dying well typically requires advance care planning. We affirm that nothing can separate us from the love of God in Christ Jesus. At the same time, we are faced with options for treatment at the end of life that can needlessly increase our pain and suffering without providing any discernible, offsetting benefit. And while we should try to be brave in the face of pain and suffering, we should not idolize it. We can, therefore, choose to refuse interventions that do nothing to sustain our relationship with God or with other persons. As such, engaging a congregation in advance care planning represents an important task of pastoral leadership and there are ways in which it can be folded into regular pastoral activities. For example, challenging church members to write an Advance Directive consistent with their values could be part of a Lenten observance. These directives also could be kept in a confidential file in the pastor's office, easily retrieved by the pastor in the event of a health crisis.

3. While it is true that many people are reluctant to discuss death and dying, a pastoral leader should be someone who gives permission and encouragement to express feelings about these difficult topics. Persons facing death typically want to talk about their fears and concerns, but are reluctant to burden loved ones or friends. Having another person with whom to confidentially share strong feelings can bring release and healing. In addition, a pastoral leader can facilitate such conversations with family members in order to reduce the isolation experienced by someone with a terminal illness.

Not talking about death has consequences, both for those who are dying and for those who love and care for them. Consider the following case study:

Mr. Paul[13] was an elderly gentleman, long retired, who lived with his elderly wife. Fortunately for them, their daughter Patty, a relatively young widow, and her three brothers lived in the same small town. Patty lived about a mile away, and as her parents grew more frail, they would ask her to drop off a loaf of bread or a quart of milk on her way home from work. Thus, she saw them briefly almost every day. Her dad would always call her by her childhood nickname and ask her how her day had been. Since his days were spent at home, he rarely had any news to impart. So Patty's reports became essentially monologues about her own life and daily activities.

One day, Patty's father announced that he and his wife were planning to drive from OH to FL to see his older brother. Patty decided she should accompany her parents because of their advanced ages, and it was on this trip that she first became aware of his advanced dementia. The trip started with her dad driving, and Patty quickly discovered that his wife had to tell him when to go, stop, what lane to be in, and when to turn. Patty quickly took over as driver against her dad's protests. In FL, his brother asked him to make his famous red pasta sauce for dinner one night and, to Patty's horror, her dad could not do it, even with her help.

When they got home from this trip, she made him go to his doctor for an evaluation, and his physician diagnosed him with advanced Alzheimer's. Her mother, however, refused to accept the diagnosis and insisted that her husband just needed to eat better and move about more. She believed that her husband would become well again.

Within a few months, he became totally confined to his bed, but Patty's mother continued to refuse any outside help caring for him and repeatedly rejected the idea of hospice. Eventually Patty was forced to quit her job to provide him in-home care for the remaining months of his life. Until the day of his death, her mother continued to insist that if he just ate more he would become well again.

Because we live in a death-denying society, many people find it extremely uncomfortable to talk frankly about death and with the dying. While it is always wise to let them lead the conversation, most dying people want to review their lives, to remember important life events, and to measure their lives against the standards and values that they espoused throughout their years. This revisiting and recollecting can be an important source of strength and solace to them. It affirms

the impact their life has had on loved ones and friends and reassures them of their value to others. However, being surrounded by people who tend to avoid such conversations creates a sense of isolation for the patient. In the story above, not only was Patty's dad isolated, particularly once he was homebound, but Patty also became isolated by the duties of caring for him. Her mother's rejection of support mechanisms such as hospice exacerbated this problem. Support from her three brothers and their wives was minimal, which essentially left Patty to carry this burden alone.

The old adage, "Where's there's life, there's hope" highlights another reason that conversations about death or even with the dying are so uncomfortable. Many people fear that to admit or even hint that someone is dying will destroy hope, which is necessary for life. Even physicians cite fear of destroying hope as one reason to be less than forthcoming with patients who are terminally ill.

The notion of hope can have many dimensions. Often when we speak of hope we mean that an ailing person will become well again. Similarly, physicians are trained to "fight" disease and so when they speak of "hope," often they mean, "hope for a cure." But the term *hope* can have meanings beyond this. Patients considered terminal may hope for a more promising second opinion. They may hope that their therapy will give them added months to complete a project or to see a child or grandchild graduate or to make peace with a friend or relative. They may hope for healing in their relationships and in their emotions even if their illness will not be cured. They may hope for a peaceful death with the support of loved ones and of palliative and hospice care.

For Christians, however, "hope" has an even a richer meaning still. We proclaim hope in the faithfulness of our God who created us and will never desert us, even as we are dying. As the 23rd Psalm affirms, "Thou art with me," even in "the valley of the shadow of death." Paul reminds us that "we may not grieve as others do who have no hope" because we have Jesus' assurance that, while death changes our existence, it does not end it.[14] Therefore, although it is painful and ruptures our most profound *human* relationships, death does not have the final word. Instead, our God—Creator, Redeemer, and

Sustainer—holds the final word, and that word is eternal life in God's presence.

1. Hospice and palliative care are often misunderstood, conflated with the management or even the promotion of death. However, in the context of seeking wholeness, pastoral leaders may in fact explore these options as an opportunity for the promotion of life. It is important that palliative care should not be understood inherently as hastening death. Rather, palliative care helps manage various symptoms and can be used in conjunction with potentially curative treatment. In the same way, hospice care should not be viewed as "giving up." Instead, it is one among several options that may actually provide the best opportunity for living in the face of certain death from a terminal illness. It is noteworthy that a multidimensional approach to the management of both physical pain and existential suffering has been shown, in some circumstances, to actually extend life even beyond that achieved through aggressive treatment with chemotherapy and/or radiation.

2. Perhaps most importantly, pastoral leaders can seek to practice the presence of Christ with dying persons. Walking into a hospital room to read scripture and say a prayer without taking the time to sit and listen to the patient results in a very limited pastoral experience for the patient. Instead, one should listen for expressions of pain, worry, anxiety, and suffering. Reflecting the patient's emotions and concerns back to the patient demonstrates compassion and reassures the person that the pastor has heard what he or she is experiencing. Consider the following conversations between a pastor and a patient in the hospital:

Pastor:	*Good morning, Ms. Smith! How are you feeling today?*
Patient:	*I'm still in pain. I could barely sleep last night.*
Pastor:	*I'm sorry to hear that. Let me read this psalm to give you some comfort. (She reads the Twenty-third Psalm.)*

Patient: *Thank you, pastor.*

Pastor: *Let me pray with you. (She holds the patient's hands and speaks a brief prayer requesting God's comfort and healing.)*

Patient: *Amen.*

Pastor: *I need to be going. I have some other patients to see in the hospital. Good-bye and God bless you.*

The following is an alternative and more compassionate conversation:

Pastor: *Good morning, Ms. Smith. (The pastor pauses, carefully observing the patient's facial expression.) You appear to be in pain.*

Patient: *I had a terrible night. The pain never goes away completely.*

Pastor (taking a seat and looking directly at the patient): *Tell me about what brought you into the hospital.*

Patient: *I was perfectly well until about two weeks ago….(The patient describes her illness and the treatment she has received.) I don't know how much longer I can bear this.*

Pastor: *It sounds like you feel pretty desperate.*

Patient: *I do. I'm so afraid of what this could be.*

Pastor: *What do you think might be the matter?*

Patient: *My father died from cancer and had terrible pain in his bones, just like the pain I have.*

Pastor: *I can see why you are worried. (Pause. The two sit in silence for a long minute.) What might I do to help?*

Patient: *Would you say a prayer with me?*

Pastor: *What shall I say in our prayer?*

Patient: *That I want to get better and go home.*

Pastor: *(The pastor says a prayer that communicates the patient's fears and desperation. It also speaks of God's presence and abiding love even in the midst of her pain and suffering.)*

Pastor: *You know that you can talk to me about anything that worries you.*

(The pastor pauses a minute to give the patient an opportunity to express other concerns.)

Pastor: *I'll be back to see you in a few days. If you've been discharged, I'll call you at home.*

Patient: *Thank you, pastor.*

The difference in pastoral presence in the two encounters is evident. Both convey pastoral concern, but the second demonstrates compassionate concern about the patient's individual experience. Only when there is some understanding of the patient's emotions and goals does the pastor say a prayer—a prayer that incorporates the patient's feelings while affirming God's presence and abiding love. This sort of engaged and caring presence carried out with the patient (and family when appropriate) communicates Christ's presence in ways that are beyond words.

As noted above, a second question of great import to pastoral leaders is: *How can I as a pastor fit in to the healthcare setting?*

To answer this question, we first need to clarify the roles of key players in that setting. What follows are descriptions of various roles played by members of the healthcare team, including clinical ethics consultants, chaplains, social workers, patient advocates, nurses, and physicians. Once clarity is established about the functions of each of these, the role of pastoral leaders and the ways they fit into the healthcare team can be elaborated.

Clinical Ethics Service/Healthcare Ethics Committee

In 1992 the Joint Commission[15] mandated that all of its accredited hospitals have in place a means for addressing ethical concerns. Depending upon the institution, this may include an ethics committee, individual ethics consultants, a formalized clinical ethics consultation service, or an ethics

forum. This was an important moment in promoting ethical, patient-centered care because healthcare ethics committees or consultants serve as a valuable resource for those working through difficult healthcare situations and decisions. They serve an advisory role to those involved in decision-making processes where ethical/moral issues are not yet clearly resolved. This includes not only healthcare providers, but also families and patients themselves.

Ethics committees often include persons from a variety of professions, including medicine, nursing, pharmacy, chaplaincy, law, social work, academic philosophy and theology, healthcare administration, and community members. Such committees may be standing (functioning on an ongoing basis) or *ad hoc* (brought together for a specific task and dissolved at the completion of that task). Each institution has a process for requesting a consult. In most cases a formal request for consultation may be initiated by the patient, patient's family, or members of the healthcare team. In some cases, however, patients or their families may need to route the request through their physician or another healthcare provider.

With so many players involved in a patient's care, conflicts of values can arise within and among the cadre of caregivers, as well as among families and the healthcare team. One role of an ethics committee is to remind all those involved in a conflict that they share an important piece of common ground: a desire to do what is "best" for a particular patient. Focusing on this commonality rather than their differing versions of what is "best" will often allow the conflict to de-escalate and those involved to hear the views of others more clearly. However, ethics consultants also can play the role of arbiter not only by listening to and building collaboration between various, sometimes opposing positions, but also by informing patients, families, and healthcare providers about important ethical considerations of which they might not be aware.

Chaplains

Healthcare chaplains are clergy employed by or otherwise in a formal relationship with hospitals, hospices, and other healthcare settings. Chaplaincy may be their exclusive ministry, or they may also serve in traditional parishes or other settings. In their role as chaplains they care for patients, family members, and staff within a healthcare institution. That is, their responsibility is defined by the healthcare institution rather than for a group of parishioners with a particular religious affiliation. While most Presbyterian ministers have received at least three months of Clinical Pastoral Education in a hospital setting as part of their required seminary curriculum, hospital chaplains typically have received at least one year of supervised Clinical Pastoral Education and also participate in continuing education.

Abigail Rian Evans writes that the clergyperson in healthcare settings, "conveys the symbols of health and healing, relating to people as persons, not as patients. . . . As people face sickness and struggle to regain some wholeness, they are challenged to accept and overcome the undeniable fact of their fragility. Symbols of healing may involve sustenance in the face of pain and suffering—assisting people to live in the midst of their brokenness."[16]

The progression of illness and the dying process often bring with them concerns beyond physical deterioration and death. Among these are questions of meaning, purpose, leave-taking, afterlife, and legacy. Some of these concerns might be stated in more traditional religious language as "getting right with God" or "preparing to meet one's Maker." Chaplains assist those working through these deep questions that go to the core of who we are as persons.

Chaplains collaborate with and care for persons fundamentally by being present with them as they journey through illness and end-of-life struggles. Chaplains offer an ear tuned to the spiritual and serve as a reminder of, and connection to, the community of faith. This presence is especially important when there is a great physical distance between the person at the end of life and her or his home community of faith. Whatever the

distance, a chaplain provides spiritual support that should add to, though not replace, a home community of faith. Chaplains should encourage the maintenance of the relationship between the dying person and his or her home pastor and congregation.

The time a chaplain spends with a person at the end of life should focus on presence rather than preaching. Often that means more listening than speaking. That listening should also be active rather than passive, open to a person's feelings and acknowledging them as they emerge in conversation. Persons at the end of life may have intense emotions and profoundly difficult questions. Chaplains provide care by being a sounding board, a conversation partner, a confidant, and a messenger of God's love and grace.

Chaplains carry out their roles in many ways, recognizing that each individual and each situation is unique. Moreover, in keeping with the notion of life as relational, chaplains engage both patients and their families. Spiritual practices, such as reading scripture, prayer, anointing, and administration of sacraments, may be accompanied by exercises in life review or visualization of the future.

Social Workers

Social workers are licensed or certified individuals with a degree in social work, who assist persons in need by performing a variety of assessments (e.g., impact of health status, housing, financial, psychosocial, availability of and access to community resources) and by developing a plan of treatment and intervention based on those assessments. Social workers in healthcare institutions are expected to have specialized knowledge about the implications of illness and injury on a person and his or her significant others. Often the task of a social worker is to make connections between a person with needs and the resources appropriate to meet those needs including civil and community programs that offer benefits to which a particular patient may be entitled. Social workers are employed by hospitals, skilled nursing facilities, hospice teams, and also often serve on palliative care teams.

Perhaps the International Federation of Social Workers summarizes it best:

> *Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing.*[17]

Ombudsman/Patient Advocate

Many healthcare institutions have a designated person or persons who help patients and families navigate the complex health system and mediate conflicts that may arise. An ombudsman or patient advocate often is not a healthcare professional but can help by listening to patient's or family's concerns and then voicing, or assisting the patient or family in voicing, those concerns to the appropriate medical team or hospital administration members. They may assist with a wide range of issues, including access to care, the amount and kind of communication a patient receives from the medical team, understanding movement between levels and types of care, and billing issues. When communication between the patient/family and an institution or healthcare team is strained, an ombudsman or patient advocate is often helpful.

Nursing

The nursing staff of a hospital, long-term care institution, or hospice facility usually includes both licensed (RN, LPN/LVN) and unlicensed (CNA, NA) personnel. Nurse practitioners have advanced degrees and advanced clinical training that affords them diagnostic and prescribing privileges. They are therefore classified as medical personnel. Other licensed

nurses, such as RNs, have more limited, but nonetheless important responsibilities. They develop plans of care and provide the broader range of needed care for a patient (administering medicine, drawing blood, wound care, assisting with various daily functions, recording data, etc.). Unlicensed nursing personnel, such as nursing assistants, also provide direct, hands-on patient care including assistance with activities of daily living, e.g., bathing, dressing, eating, toileting, but are restricted from some other nursing duties (e.g. medication may be administered only by licensed personnel).

Given a societal context in which body image is often distorted, many patients are uncomfortable not only with physical death, but with their physical bodies, in general. They may worry that others are repulsed by their appearance, particularly as they start to experience more severe physical declines. Members of a nursing staff are particularly well positioned to demonstrate respect and comfort in caring for the body. As decreased physical and mental capacity accompany the approach of death, patients become increasingly reliant on others for tasks that they have previously performed for themselves. Nursing personnel often take over these tasks. When working in a manner that demonstrates competence, kindness, and respect, nursing personnel acknowledge the humanity of those who are dying and may be able to lessen a patient's feelings of powerlessness, worthlessness, and the emotional discomfort that attends bodily decline.

Pain control is often an important issue for those near the end of life. Nurses assess patients for pain, administer pain medications ordered by medical providers, and use non-pharmaceutical techniques (e.g., re-positioning, application of warmth/cold) to reduce or relieve pain. For some who are dying, there is the desire to have all pain relieved, even if that means loss of alertness or decreased mental capacity. For others mental acuity is more important than physical comfort, and some find pain to be an indicator that one is still alive. For these individuals, complete relief of pain may not be the goal, particularly if it cannot be accomplished without sacrificing other things of greater worth to the patient. Nurses care for patients in pain by listening to their concerns and by educating them on available palliative options and their side effects.

Education is a major component of nursing care. Nursing personnel trained in end-of-life care are able to provide information regarding the dying process, including particular physical changes that most people experience as they near death. Personal and cultural discomfort with death itself, and with the bodily changes that often accompany it, can be strong. Many persons have not encountered those who are dying and are not familiar with the attendant changes in appetite, sleep patterns, energy levels, bodily functions, and the like. Nursing personnel can ease concerns of patients and their families by discussing changes that are happening or will likely happen as disease progresses or death nears.

The primary nurse caring for a patient in the hospital often is the most knowledgeable about the patient's concerns and condition, as well as the family dynamics. Although nurses (and other healthcare providers) are limited by law regarding what information they may share about a patient and with whom,[18] a brief conversation with the primary nurse before the pastor enters the patient's room may lead to valuable insights into how the patient is feeling that day and any particular joys or struggles he or she might be having.

Physicians

Depending upon the complexity of a patient's problem and the level of care required, from the general medical floor up to more intensive, critical care units, there may be many different kinds of physicians involved in a patient's care. Furthermore, it is becoming more common for hospitalized patients to have a hospitalist, not their own personal physician, coordinating their care within the hospital. Hospitalists are typically employed by a hospital to be the physician of record for inpatient care. Most patients meet their hospitalist for the first time when they get admitted to hospital. Because of this, and the numbers of different specialists and other healthcare providers that come and go during their treatment, many patients can't remember the name of this physician who is ordering the tests and the treatments they receive.

While the physician of record is the "quarterback" of the healthcare team looking after the patient, it is truly a team enterprise. Patients and their families may often be confused when different sub-specialists render different opinions about how the patient is doing. Their opinions and perspectives often emerge from their particular clinical expertise, often focused on a specific organ system. For example, the cardiologist may comment on a heart problem he can fix with medication, but the pulmonologist reports that the lungs will never regain normal function. It is the primary attending physician's responsibility to help the patient and family understand the overall prognosis and plan. However, because of the complexity of healthcare today, communication may be of variable quality and misunderstandings can occur.

The Pastor's Role

As mentioned, because of the protections for patient privacy (i.e. HIPAA), the pastor usually relies primarily on the patient or family for information. Sometimes this information may be incorrect or inaccurate, however, because the complexity of health information and the often-chaotic hospital environment can easily result in confusion. The pastor must therefore be cautious about drawing conclusions about the patient's prognosis. However, although the pastor does not have access to the patient's medical record, he or she does have a critical role to play in helping individuals in their congregations to cope with illness. In fact, often the pastor's presence itself in the hospital environment reminds patients of their connection to the larger faith community that sustains us all. Above all, the pastor should make the effort to be present with the patient, whether this is in the patient's room, in a pre-operative area, or in the infusion center for chemotherapy. Beyond presence, however, there are things a pastor can do that can be of great help to a patient.

First, the pastor can be sensitive to bias when it appears to result in misunderstanding or discrimination. For example, does the pastor detect that the healthcare team is making assumptions about the patient's values? This mistake may

occur particularly where healthcare teams have a poor understanding of particular faith-based perspectives held by the patient. In such cases, pastoral leaders may have opportunities to facilitate understanding between the healthcare team and the patient.

Second, the pastor can offer to participate in ethics committee deliberations, if these arise, provided the patient or the patient's advocate gives permission. Patients will often appreciate the pastor's willingness to be part of these discussions. In these meetings the pastor can moderate any evidence of intimidation, demonstrate appreciation of different perspectives, and facilitate positive interactions among those present. He or she may ask questions that the patient or family wished to ask but were hesitant to do so. Pastoral leaders also can provide support for patient and family perspectives, as well as clarity regarding positions taken by the church, which can provide clarity not only to the healthcare team, but also for the patient and family as they wrestle with difficult issues at the end of life.

Third, the pastor must understand the power of words and avoid making statements that seem to claim a special or full knowledge of God's purposes. Pastoral leaders should not say something, for example, that suggests the patient's illness is "God's will." Similarly, he or she should not tell the patient that his or her suffering will "build character." Such claims not only can be psychologically harmful, but may also fail to recognize the genuine mystery of God's providence. Additionally, clergypersons should not say they "understand" what a patient is experiencing and should avoid giving personal advice or comparing their own experience to that of the patient. The struggles and challenges at the end of life belong to the existential terrain of the patients themselves, and when someone else claims to understand or share those particular experiences it robs the patient of his or her particular experience, moving it instead onto the terrain of the pastor. Above all, the pastor is called to listen to the patient's experience without judgment and to accompany the patient in that experience, providing companionship and attentive care. Pastoral presence should offer a safe place for the patient to express feelings and concerns.

The sensitive pastor quickly will be aware of a tension between the culture of a hospital and the culture of the patient's faith community. The hospital culture is characterized by a focus on the individual patient, a desire to either cure disease or transfer the patient to a long-term care facility, and a general uniformity in the way the right course of action is determined for patients. It can therefore be difficult to reconcile this healthcare culture with situations where broader faith communities are involved, disease is incurable, or when the patient has unique needs, perspectives, or beliefs that require deviating in some way from the well established habits of the healthcare team.

When healthcare professionals discuss medical ethics, it is typically in the context of four principles:

1. **Autonomy** – Respect for patient self-determination regarding the treatment received by the patient

2. **Beneficence** – Doing what the physician believes will benefit the patient

3. **Non-maleficence** – Not doing anything that harms the patient

4. **Justice** – Providing non-discriminatory treatment to all patients through a fair distribution of available medical resources

While these principles provide a relatively comprehensive, secular context for considering ethical questions and dilemmas, they can at times conflict with each other (autonomy with beneficence, for instance, in surrogate decision making), and they may not always fully accord with faith-based perspectives. The principle of autonomy, for example, can make sense of a patient decision that emerges from a particular spiritual conviction because it can be understood as a basic right of patients to exercise their own beliefs. It is important to recognize, however, that respect for autonomy does not require that healthcare workers actively understand the patient's

beliefs and perspectives, only that they acquiesce to them. Pastors, therefore, can push the collaboration of patients and the healthcare team further, going beyond the basic agreements elaborated by these four principles and towards a more genuine, more robust understanding of each other.

It is also important to recognize that other ethical theories are often more illuminating and helpful in end-of-life circumstances than are consequentialist and rule-based theories. Ethics of care and other virtue-based philosophies focus on the qualities of character needed by decision-makers in end-of-life cases. Emphasis is placed on the embodiment of particular virtues and less on particular actions per se. The language in past Presbyterian statements about covenants of care clearly has an affinity with this paradigm of ethics.

Healthcare institutions also can be intolerant of ambiguity and organized around a "chain of command" for decision making. This rigidity creates a potential for conflict on two accounts. First, a person's religious beliefs introduce an ambiguity for healthcare providers who may then have to reflect on and reconsider various practices to which they are accustomed. Second, while it is more acceptable today to question a physician's decision than it was in the past, there remains an assumption that the physician has the patient's best interests at heart unless proven otherwise. Of course, the degree to which this is true depends on the physician's attitudes, approach to end-of-life care, and knowledge of the patient and the patient's values/goals of care.

Insofar as they are not subject to the hospital chain of command, pastoral leaders may be more willing to question whether the patient's values are being honored than members of the hospital staff. More importantly, the pastor brings to the patient a connection to the faith community, which can alleviate the isolation a patient may experience in the hospital setting. The patient is not simply another individual in the hospital. Rather, he or she is part of a community that, at its best, provides hope, comfort, and a sense of belonging. This fellowship has a healing effect of its own. Furthermore, the pastor can affirm the value of wholeness as something more meaningful and lasting than cure. Representing this holistic vision in the midst of the sometimes countervailing habits and

practices of healthcare providers is important in promoting the best possible end-of-life experience for patients who might otherwise be swept up in healthcare decisions that do not accord with their beliefs and perspectives.

III. For the Community of Faith

We live in a 21st century American society that often glamorizes youth and denies the reality of death. Most people avoid thinking about death until they or a loved one receives a potentially fatal diagnosis or dies suddenly. The social landscape whereby family members now spread themselves across larger distances exacerbates growing feelings of disconnectedness and complicates decision making at the end of life. Decision making in the midst of a crisis, without intentional forethought and planning, too many times leaves people wondering later, "Why did we ever make those decisions?" or "Why did we insist on subjecting our loved one to painful, invasive and ultimately futile procedures?" This sort of second-guessing highlights another reason that thinking about end-of-life issues *before* we are faced with them is so important. Not doing so can result in choices that leave family members feeling guilty and remorseful.

Much of the thinking about end of life that needs to be done is spiritual in nature and properly belongs within the framework of a person's religious tradition. It is, therefore, entirely appropriate for pastors to raise end-of-life issues with their congregation and encourage them to engage in advance preparation rather than leaving decision making to the bedside in an ICU. Death is not optional, but part of God's ordering of creation. Our Reformed theology teaches that one form of human sinfulness is "our inability to live in a relation of trust and obedience to God, seeking instead to take charge of our own destiny and guarantee our own life." This form of sin is "a mistrust of God's intention and/or ability to nurture and sustain us, and one of its chief results is the fear of and denial of death."[19] Ultimately, victory over death is necessarily divine, not technological or scientific.

Many who face death are geographically separated from their closest family members. This distance in its own way contributes to the denial of or refusal to come to terms with death. Many family members (and others who live at a distance) are often not fully aware of a person's physical and mental declines and find it difficult to accept that death is

nearing. It is not uncommon for an individual to face the approach of death with little family presence or other support.

In the midst of this situation, the community of faith tells us we are not alone. As the scriptures and confessions remind us, in life *and in death* we belong to God, and "even in the valley of the shadow of death, we need not fear. God is with us." Members of the faith community in the love and care they provide represent a gracious reminder of this. As Amy Plantinga Pauw has noted, "Those who face death experience the living presence of God through the living presence of the community that cherishes and mourns them. And the community members who cherish and mourn these deaths are at the same time preparing themselves for the deaths that will surely come to them someday."[20]

So what kinds of questions should faithful Christians think about before they face a life-threatening illness? One important issue concerns the intersection of the widely held belief in the sacredness of human life with the application of life-prolonging medical technology. Some faithful people say that our lives are sacred because they are "a gift from God." In our faith tradition, the sacred nature of human life emerges from the claim that humans are created "in the image of God."[21] In the medical community in the U.S., the notion of life's sacredness has been translated into the widely held view that doctors should not act deliberately to end a human life.

However, does our belief that God is the giver of life mean that under all circumstances we are morally obligated to postpone death as long as possible? Confusion about the particular moral requirements engendered by the sacred nature of human life sometimes play out in family conflicts in the ICU. Some family members opt to follow the patient's wishes as stipulated in their advance directive, which may include limits on the extent to which they wish their physical life to be prolonged by aggressive medical interventions. At the same time, others may stand across the bed from those same family members, often with their pastor, and point out that only God should decide when a particular life should end. For them, actions to end unwanted medical treatment, like turning off a ventilator, are "trying to play God." Congregations will benefit from pastoral guidance in thinking through such conflicts.

It is important to understand that medical professionals, especially physicians and surgeons, historically have been trained in a system where medicine is explicitly and implicitly conceived as a "war on death." This "war on death" metaphor arose as medicine was beginning to have unprecedented success in treating infectious disease. But it gained a great deal of additional momentum throughout the Twentieth Century and into the Twenty-First, with an explosion of medical technologies like antibiotics, ventilators, dialysis machines, and new imaging technology that give physicians even more powerful new tools. Early successes treating infectious diseases led medicine to act as if, by declaring "war" on each disease one by one, death itself could be eliminated from human life. This foundational metaphor persists in various formulations, often leading doctors to view the death of a patient, no matter how old or sick, as a "defeat" at the hands of an implacable "enemy." Thus, some doctors will go to great lengths to postpone death even when it becomes clear that, for an individual patient, there is no credible hope for survival, let alone a return to health. A family panicked by an unexpected medical crisis encountering a medical system whose ethos is "keep fighting at all costs" with constantly-expanding technologies, creates a "perfect storm" whereby dying is turned into a prolonged and painful process. Ethical and spiritual reflection has not kept pace with the burgeoning of technology, which means there often is little discussion about the goals of care. This lack of preparation and discussion results in the application of treatments that may not align with the patient's true values and desires.

Death ruptures the most profound human relationships, and certainly no one welcomes the loss that accompanies a loved one's death. But since God's ordering of creation includes the death of living things, we all face death at some point. So the challenge for Christians concerns *how* to approach the inevitability of death faithfully, and that approach includes planning for how we wish to die.

Hospice and Palliative Care

Part of thinking about the end of our lives includes becoming knowledgeable about hospice and palliative care, two evolving options for medical care at the end of life. At one time death was a fairly discrete event. Most life-threatening accidents and illnesses were fatal within a few days. Modern technology has now turned dying into an often months-long process. This intensive use of technology also means the dying person must be in a medical facility where skilled professionals apply and monitor these machines. But while the reality is that the vast majority of people, particularly those who are older, die in a hospital or nursing home, about 80% of people, when asked, report that they would prefer to die at home, in familiar surroundings and with family in attendance. Hospice is one alternative that can make this possible.

The usual goal of medical care is to cure illness or extend life. This effort often means sacrificing the quality of a person's life in the immediate in an effort to gain more time later on. Hospice helps people with a terminal illness have the fullest possible lives in the present by focusing on the relief of pain, maintaining awareness as long as feasible, and supporting the patient and family in meeting the patient's goals of care.

Hospice is a program, not a place. Hospice care may be provided in any setting: in the patient's home, assisted living facility, nursing home, or in some cases the hospital. Residential hospice houses, where available, offer hospice care that is covered by Medicare and most insurance plans. These plans also cover medications, equipment, and supplies related to the terminal condition, but require additional payment for room and board expenses. Importantly, the hospice benefit does not cover treatment primarily aimed at curing the underlying terminal illness (like chemotherapy). Hospice provides care through an interdisciplinary team consisting of registered nurses, nurses' aides, hospice physicians, social workers, spiritual care professionals, and volunteers. Patients may choose to continue to collaborate with their personal physicians, or may choose to have the hospice physician manage their medical needs. Although hospice is available 24/7 to address patient needs, it does not provide around the clock

care. Rather, the various members of the care team usually visit at regular intervals as determined by the patient's needs. Patients can receive continuous care or be admitted to the hospital for inpatient care in the event that symptoms cannot be managed at home. If sitter services are needed, hospice usually can provide a list of sitter services for hire.

Patients can be referred to hospice from another physician, but may also self-refer for an evaluation to determine eligibility and gain information related to their particular situation. A hospice agency will assess patients and admit them only if it is determined that the patient's prognosis suggests they will live only six months or less. The hospice team will follow the patients until they die, providing coaching, emotional support, education about physical and mental declines, and assisting with paperwork, funeral planning, and notifications after death. Bereavement support also is available to loved-ones for one year after the patient's death.

A patient may receive hospice services as long as the hospice physician continues to certify that the patient's life expectancy is six months or less. This is determined by a set of specific medical criteria in concert with the hospice physician's clinical judgment. If a patient lives longer than six months, the hospice benefit may be extended, provided the hospice physician feels that the future prognosis continues to be less than six months. However, if the patient's condition improves or becomes chronic, and it appears that the patient will live longer than six months, the patient must be discharged from hospice. That patient can, however, be readmitted when medical decline recurs.

A persistent myth about hospice programs is that people should wait until just days before death to start hospice care. Unfortunately, the median length of stay in hospice in the U.S. currently is less than one month. This is not long enough for hospice to offer the range and depth of support and education that it is capable of providing. Hospice teams are particularly well versed in dealing with pain and other symptoms that occur at the end of life, and they can provide relief from suffering that may be neglected or overlooked with conventional care. Patients often improve for a time when pain and other symptoms are well controlled. This respite allows for

more quality time with families and loved ones. Much to their amazement, friends and families sometimes find that the dying process, when well-managed and with excellent pain control, actually can be a time of personal and family growth as people act out the virtues of compassion, faithfulness, and mutual support for their dying loved one.

While hospice includes palliative care, not all types of palliative care constitute hospice. Palliative care is a relatively new medical specialty aimed at managing symptoms associated with chronic or terminal illnesses that are troubling to patients, but often ignored or undertreated by other medical specialties. Unlike hospice, a determination that an illness is terminal is not required before receiving palliative care, so it can be provided even while a person is receiving other therapies such as chemotherapy or radiation. Many hospitals have palliative care teams that can provide consultation when a patient is hospitalized and, in some communities, outpatient consultations and home visits are offered as well. Like hospice, palliative care is focused on improving symptom management and the quality of patients' lives as much as possible, given their medical condition. This amelioration includes attention to the emotional aspects of serious illness and offers support to patients and their families. However, outpatient palliative care is a medical consultative service and does not provide nursing, nursing aids, spiritual care support, medications, supplies, bereavement support and other services offered under the hospice benefit.

Advance Directives for Health Care

As discussed earlier, people now have the ability to create **advance directives**—legal documents that outline the types of medical care and procedures they want or do not want at the end of their lives, or *whom* they wish to entrust with those decisions—based on their personal values and religious traditions. Each state has its own statutes authorizing these documents, so the exact document titles, their terminologies, and the range of documents constituting legal advance directives vary by state. The bar association websites in each

state usually are a good place to find the necessary documents to create an advance directive that meets state requirements.

One kind of advance directive available in many jurisdictions, is called a "living will," sometimes also called a "health care directive." This document allows an individual to specify desired and undesired forms of end-of-life care, including resuscitation instructions, desired medications for pain, and the individual's preferences regarding life support devices if they become unable to communicate. Its originator can revoke a living will at any time.

Another type of advance directive document is called a "durable power of attorney for health care" or DPAHC. This is not to be confused with a general durable power of attorney, which authorizes a named person to act on behalf of the signer in conducting business affairs, managing or selling property, and the like. A DPAHC appoints another person, called a proxy, to make health care decisions for the individual who created the DPAHC when (*and only when*) that individual becomes incapable of making or expressing decisions about treatment. Designated proxies can authorize or reject specific treatments (whether or not these are specified in a living will or other written instruction) based on their knowledge of what the person who appointed them would have wanted. DPAHC statutes and documents also encourage the appointment of a secondary proxy, to be consulted in case the first-named proxy cannot serve when needed.

There are a number of ways that states vary from one and other in their requirements for advance directives. Some states allow persons to make either a living will or a durable power of attorney for health care; either document is referred to as an advance directive. Other states combine living wills and durable powers of attorney into a single document. Further, some states require formal notarization of these documents, while others require only that the signature be witnessed when the document is signed. Finally, some states also require that the person named as healthcare proxy or secondary proxy also sign the document, indicating his or her willingness to accept that responsibility.

Before filling out an advance directive document, however, it is important to think about one's personal values and wishes regarding one's end-of-life care. One way to do this is to imagine you are facing an incurable illness and a significantly shortened life span. How would you want to spend your remaining time? What important life projects are you working on that you really want to complete? What things are on your 'bucket list'? Are there important upcoming family events—graduations, weddings, births, anniversaries, or the like—that you especially want to attend? These personally important goals are good stopping places on the journey of thinking through the many choices about medical care that will confront you now when and if you have an actual terminal diagnosis. They help guide whether you would want to prioritize quality of life or quantity of life or some place on the continuum between those two considerations. The choices you make about these goals will help you sort out how much weight you will want to give to the various treatments available for prolonging your life.

For example, if *quantity* of life is most important to you, then you might be willing to go to a distant cancer center for treatment even though that means time away from family and friends. If quantity of life is your primary goal, then the benefits of life-prolonging treatment will count more than burdens. Similarly, if prolonging the quantity of life you have is most important, you might want to choose to authorize long-term life-support on a respirator in a nursing home. If, however, you favor *quality* of life so you can enjoy as much as possible time spent with family and friends and the ability to function such that you can pursue your bucket list, then you might, based on those personal goals, say that the potential burdens of some forms of treatment will be too intrusive to be worthwhile. There are many, many variations on these themes that you might choose, so it is a tremendous help to have thought, even if hypothetically, about these choices before you actually have to make them. Of course, your age and general state of health at the time of your diagnosis also plays a vital role in the choices you make, so as people age and their health changes over time, it is important to revisit these considerations.

One of the most important decisions you make in executing a DPAHC advance directive concerns the person that you choose to be your healthcare proxy. Since it is impossible to know in advance the circumstances of an individual's final illness, it is imperative that your proxy knows you and your wishes well enough to determine what you most likely would have wanted in your circumstances. Therefore, you and your proxy should spend some time in conversation about your wishes is an much detail as you can imagine, given that your final illness is only hypothetical at this point. Moreover, although your DPAHC is a legally and morally binding document, your proxy must be prepared to hold your medical team accountable for honoring your wishes for and against treatment. Some people find it hard to disagree with what physicians recommend. Such a person may not make a good proxy. In short, a good proxy would ideally make the same decisions you would have made yourself and have the tenacity to advocate for those decisions in the face of opposition.

Often family members are chosen as the proxy because they tend to know us best. However, with families now often scattered around the globe, the person who knows you best *might* not be your son who works in Singapore or a daughter who lives on the other side of the continent, but instead your next door neighbor who takes you to doctor's appointments and picks up your medications at the pharmacy. Additionally, family members sometimes disapprove of the choices a person wants for him or herself. This can make it too emotionally difficult for them to insist with any tenacity that doctors honor the patient's particular choices when they themselves do not condone them. In this case, you might want to think about asking another person to be your proxy. If you think that a close family member is seriously conflicted by your choices, it is best to work through that with them while you are still healthy. It is wise to have a frank discussion with this family member about what you want or don't want in terms of treatment at the end of your life. Your goal should not be to get them to change their position. Rather you should seek their agreement to honor your choices because they are yours and out of their love for you. It is important to note that this does not require they would make the same decisions for themselves, and your choices should not be read as a judgment about theirs.

Coming to these agreements often prevents the desperately sad scene described above in which some children want to follow the advance directive and others argue passionately against those choices because they see them as immoral or an "attempt to play God." In the event that you decide that a non-family member is the best choice for your proxy, it is also wise to let your family know this in advance so they are not blindsided by that information in the midst of a crisis situation. You will also need to recruit at least one successor proxy in case for some reason your first choice is unable to serve when needed. Sitting down with a trusted clergyperson to map out what is important to you may also be helpful.

Your proxy needs to have a copy of your advance directive, as does your primary physician and your local hospital, which usually will scan it into your medical record so it is readily available. The proxy also needs to be able to locate your document at a moment's notice, so it is not appropriate, for example, to keep it in a safety deposit box that is inaccessible to the proxy. If your church has confidential files, it may be willing to keep a copy of your advance directive locked up in the church. Since pastors are among the first to be notified when a crisis arises, they can be helpful in providing this critical document if they have a copy. If you have a personal attorney, giving him or her a copy is also a wise idea.

As has been noted previously, most of us live in a death-denying and mobile society. The community of believers gives itself a great gift, and gives society a needed example, by acknowledging death and lovingly accompanying those approaching the end of life. The community blesses individuals when it is unafraid to face and speak of death. It offers the opportunity to express deep emotions related to death and loss and a safe environment in which to do so. It also encourages thoughtful planning, helping to initiate important end-of-life conversations among family members and between individuals and their healthcare providers. In all of this the community of faith lives out the Good News of love, care, and hope that we have been given in Christ Jesus.

IV. Special Concerns or Circumstances in End-of-life Planning

1) End-of-life planning and care for chronically or severely disabled persons

One of the great concerns of those who are chronically ill or severely disabled, and especially those with intellectual and developmental disabilities (IDD), is that their lives are viewed by others as less valuable than the lives of persons without evident disabilities. People living with significant disability are not different in the most important ways from those living without those challenges. They live their lives fully, adapting in often-remarkable ways to a society that is designed around ability and independence. They sometimes depend on others to help them compensate for lack of capacity to accomplish certain tasks independently, as we all depend on others for help under various circumstances. Thus, those with disabilities teach us all about the interdependence of Christian community. One's own spirituality cannot help but be affected by the unpretentious and innocent way that individuals with IDD approach other people and life in general. Pastoral leaders must mindfully include such persons in their pastoral care and help insure inclusion of all persons in the wider church community. With this in mind, end-of-life issues involving persons with physical, intellectual, and developmental disabilities must be discussed with sensitivity toward their experiences.

Discussion about ethical decision making for persons with severe and chronic disability may tend to invoke the circumstances of their disability in addressing questions about whether a medical or surgical intervention is truly indicated. However, the decision to provide an intervention should have nothing to do with the assessment by outside observers of the value or worth of the person's life, something which is often significantly confounded by a propensity to overestimate the negative impact of the disability and its challenges. The only

person who can determine the quality of a life is the person who is living it or the surrogate who knows the individual well enough to make that determination, if the person can't speak for himself (including the parent or guardian, if the person is a child). Often, medical decision making is dominated by consequentialist ways of thinking. This paradigm has tended to focus on determinations of risk, benefit, and burden. To use terminology from the work of Paul Lehmann, it is more important for the Christian to consider how any interventions employed contribute to "making and keeping human life human."[22] Every person, no matter what her intellectual and/or physical limitations might be, should be conceived as part of God's activity in the world to make and keep human life human. The aim is the creation of communities of persons who affirm each other and the experience of a profound existential and spiritual joy that arises from that activity. This type of joy is distinct from, and more important than, more mundane notions of happiness and pleasure that often find their way into ethical decisions about the costs and benefits of treatment.

The pastor plays an important role in the hospital or nursing facility, particularly in situations involving patients with physical, intellectual, and developmental disabilities, by introducing the paradigm of "making and keeping human life human" as a balance to strictly consequentialist ways of thinking. Still more important, knowing that supporting human relationships makes and keeps us human means that decisions about interventions can be framed in such a way that promoting the individual's ability to be in relationship with others is explored as a critical consideration. There also are specific additional ways that the pastor can minister to the patient and family/caregivers:

The pastor should be aware that past predictions about the limited life expectancy of infants and children with IDD have been set aside as medical science has developed effective interventions to correct or ameliorate many congenital anomalies. As the life expectancy of persons with IDD has increased to near-parity with that of the general population, end-of-life issues have become more similar for all persons. Hospice and palliative care choices, for example, are just as

pertinent for the IDD population as for the general population. Perhaps most important, since we may have a greater propensity to be dismissive of their beliefs and values, it is utterly critical to remember that patients with IDD have the same right as others to make end-of-life choices and have those choices respected.

a. The pastor should insure that the care of individuals with IDD is respectful and reassure these persons, as well as their families and caregivers, that the church is committed to providing them the same degree of pastoral care provided to any other member of the church community.

b. The pastor should support the task of the patient, parents, and caregivers in making medical decisions together. In other words, shared decision making helps insure that the values and preferences of the patient are respected even when medical facts and recommendations may be set forth by the healthcare team as the dominant considerations. The desire to understand and work with these values and preferences, in addition to the medical facts, promotes the humanity of all involved.

c. When a patient's family makes a decision to prolong the life of the patient, and this appears only to prolong the person's suffering with very little chance of any future relational experience, the pastor can help the family to explore what love and the desire to promote the human element in the person's life suggests is the best course of action. Stated another way, pastoral leaders can encourage a discourse surrounding the best response to Christ's command to love each other, recognizing that death is inevitable for all of us, that we belong to Christ in this life and beyond death, and that a disability does not devalue the worth of a person's life.

d. As noted, it is very helpful to a family/surrogate when they can refer to an advance directive that expresses the individual's values and preferences for end-of-life care. People with a severe disability have the same

desire to live as anyone else, though this may not always be appreciated by some healthcare providers. Early formulation of an advance directive may be especially important for individuals whose bodies are vulnerable to serious disease, particularly those with a severe disability who wish their lives to be prolonged by any beneficial means possible.

2) End-of-life decisions for terminally ill or severely impaired children and pregnant women

Children who are suffering with an illness or condition that will lead to death within weeks to months, presents a significant challenge for end-of-life care. The death of a child is a wrenching loss for any parent and for all involved in the care of the child. It also raises difficult theological questions. On the one hand, we can try to recognize God's presence in the suffering and try to affirm Christ's promise never to abandon us in life or in death. On the other hand, parents of dying children typically feel abandoned by God. The belief that God is omnipotent conflicts with the narrative of a suffering God who allows God's self (Son) to be placed on a cross for a terrible death. Children, depending on their age, may blame themselves for their condition. Children's concerns usually are immediate, including things such as pain relief, opportunities for play, visits from family, friends, and pets.

The pastor has the opportunity to minister to the child and parents, as well as the medical team caring for a child in the hospital, in some very important ways:

a. Rituals important to the child and parents, e.g. prayer and communion, should be explored and made a part of advance care planning.

b. Parents often express feeling powerless in the hospital setting. Pastors can explore these feelings and facilitate discussions with the medical team and hospital

chaplains, who have training in clinical pastoral support, in order to give parents a greater sense of control, or help them find peace where they lack it, as end-of-life decisions are being made.

c. Pastors should specifically address the concern by many parents that faith in God requires that "everything be done" to keep their child alive. It is theologically justified to consider the benefits and burdens of any treatment. The concept of "caring for the child" is easily conflated with a commitment to aggressive treatment options. These options could include dialysis (to remove toxins from the body if the kidneys are failing), intubation of the trachea and use of a ventilator (if the child is in respiratory failure), and cardiopulmonary resuscitation (CPR) if the child stops breathing or the heart stops beating. These options may be reasonable if they can reasonably culminate in the return of function. However, using any of these options to prolong the process of dying presents burdens with no demonstrable benefit. In turn, limiting those types of interventions may represent a preferable way to care for the child. For example, a Do Not Resuscitate (DNR) order may be appropriate to ease the passing of a child whose death is imminent or for whom a return to meaningful functioning is not a reasonable expectation.

d. Pastors should be aware of the availability of a Clinical Ethics Consultation Service or Healthcare Ethics Committee, if an irresolvable values conflict emerges between a family and members of the child's medical team. Such a service or committee can help provide clarity in situations where there is miscommunication and conflict. The pastor can and should, if invited by the family, participate in any meetings held to contribute to resolution of a conflict. Parents who have a close connection to a church often want to know the Church's position on various end-of-life issues, and the pastor can address this in meetings called by the ethics committee.

e. If a child's life expectancy is less than six months, parents should be made aware of the availability of pediatric specialists in hospice and palliative care. These specialists can insure that the comfort of the child is a primary focus and help with the determination of whether an intervention such as artificial nutrition and hydration produces any benefits that outweigh the burdens and discomforts of the intervention. This determination is typically a concern when the child becomes unresponsive a short time before natural death occurs. It is a normal human response to want to provide nutrition and hydration artificially (see discussion below), especially when a child is no longer eating or drinking. But this form of feeding may or may not be in the child's best interest. The body is shutting down during the process of dying, and feeding can produce discomfort. Another frequent concern is the use of opioids, such as morphine, for pain control. Parents worry that opioids may hasten death by depressing respiratory drive. When pain control is used appropriately, this is not a significant issue, and these medications can insure that the child lives with minimal or no pain.

The circumstances of dying pregnant women present another theological challenge. There have been occasions when a woman dying with metastatic cancer or a devastating neurological condition has been placed on life support when death was imminent, sometimes by court order. The hope has been that the infant she is carrying might survive if gestation is prolonged for as much time as possible. Our Reformed theology does not require a specific course of action when making a decision about whether to keep a pregnant woman on life support when death is imminent or when she has already met the criteria for brain death (discussed below). The specific circumstances must be examined, and individual moral commitments and beliefs of the pregnant woman and her partner should govern whatever decision is made, in light of respecting the woman's right to govern what is done to her body.

Several specific considerations should be kept in mind:

1. Infants supported under these conditions, if they survive at all, generally have poor outcomes.

2. If maintaining the pregnant woman on life support violates her own wishes, it is not ethically defensible to impose that upon her.

3. The pastor can play an important role in having discussions with the woman and her partner to determine what is in the best interests of all concerned parties. No matter what the decision made, maintaining a pastoral presence is critical.

3) Withholding/withdrawing nutrition and hydration in end-of-life care

Normally, eating gives us fuel for life and keeps us healthy. It is also an important part of our family life and social interactions. We gather around the table not just to eat, but also to pray and to enjoy fellowship and conversation. Food is often a gift for those we care about and is a primary way in which we nurture each other.

The final days or weeks of a terminal illness normally include a decrease in the intake of food and fluid. Artificial hydration and nutrition from intravenous lines, a feeding tube surgically implanted into the stomach (called a percutaneous endoscopic gastrostomy [PEG] tube), or from forced oral intake of food and water can cause discomfort and harm. During this time, the human body is preparing itself for death and has gradually decreased its need for nutrition and fluid as bodily systems and organs begin to shut down. This decline can be a difficult time of transition for family members and loved ones who are involved in caring for the dying person. Caregivers often feel that, even when they are no longer able to offer any type of treatments, they can at least offer food. "We can't just let him starve!" is a common sentiment.

The expected and natural declines in eating and drinking in the final days or weeks of a terminal illness do not constitute starvation. At end of life, the internal organ systems are no longer able to process food and fluid, and most patients do not feel hungry during this time. Unlike a healthy person, very sick and dying persons do not experience feelings of hunger and thirst. When a person with a terminal illness is not eating, this is usually a sign that he or she is beginning the dying process. Providing fluids through an IV or PEG tube or forcing the patient to eat and drink can cause discomfort, nausea and anxiety. It can also lead to physical harm, such as increased fluid in the lungs and extremities, diarrhea, bloating, and shortness of breath.

Somewhat paradoxically, dehydration actually often affords some pain relief and can also relieve nausea, congestion, and coughing that can occur at end of life. It is recommended that caregivers allow patients to be the "guide" with respect to the amount of food and fluid they receive. As stated above, most people, when nearing end of life, don't feel like eating. Teeth clenching may be the only way a person who is nonverbal can express that he or she does not want to eat. In response, feeding should not be forced. If the patient is hungry or thirsty, offer favorite foods or drink in small sips or tastes until satisfied. The focus should be on pleasure rather than quantity or nutritional value. Keeping lips and mouth moist and clean with oral swabs will give comfort as the dying process unfolds.

Some patients near end of life begin to have difficulty swallowing. This is especially prevalent in patients with dementia. Called dysphagia, this condition can cause food or fluid to be aspirated into the lungs, causing breathing difficulty or pneumonia. Dysphagia is an expected progression of the disease process in end stage dementia and other terminal illnesses. Healthcare providers may recommend soft or pureed foods in these situations. Unfortunately, the texture of soft or pureed food is often unappealing. Patients therefore may not enjoy it and often refuse to eat. If regular food is preferred, this should be discussed with the physician. The physician can write an order to allow comfort foods for pleasure, provided the patient and family understand that there is a risk of aspiration that could cause pneumonia. Still, the benefits of enjoying food near end of life may outweigh the risk of

aspiration. Pneumonia is generally a painless way to die, while restricting a person's diet at the end of life can be associated with frustration and loss of pleasure in those final days.

A PEG tube may be recommended for patients who are having difficulty swallowing. PEG tubes are excellent "bridges" back to normal eating in patients who have a potentially reversible condition, like trauma or acute stroke. However, in persons who are actively dying and no longer able to consume food orally, the placement of a PEG tube should not be considered without serious discussion about goals of care. If it is possible, these discussions should include a palliative care team. In these situations, a PEG tube can artificially prolong the disease process and lead to a protracted death with poor quality of life. Hospice teams can provide support to family members and caregivers of patients who are no longer eating and drinking due to terminal decline, as well as to families who choose at some point in the process to discontinue artificial nutrition and hydration for their loved one.

People who have ceased eating and drinking due to their illness will gradually lose consciousness and will usually die within two to three weeks. Medical evidence very clearly indicates that this is a painless, compassionate way to die. Nonetheless, of course, a family will need a great deal of support during this time. Hospice providers are especially skilled in providing support in these situations, and a pastoral leader's involvement will be critical.

4) The roles of palliative and terminal sedation in end-of-life care

It is not uncommon for dying persons, especially those in severe physical or emotional pain, to ask their physician to help hasten their death. For many dying patients, the fear of suffering is more significant than death itself. Many requests for assisted dying actually are calls for help—either for relief of physical pain or relief of profound spiritual and emotional suffering. While pain control is sometimes neglected during

the treatment of disease, it should be aggressively pursued at end of life. A palliative care or hospice physician is particularly skilled in managing these symptoms and should be consulted if available. The risk of depression and anxiety is also significant in the end stages of disease. It is important not to overlook the diagnosis and treatment of these conditions. Spiritual and existential distress is prevalent in the terminally ill, but often not recognized by clinicians. Involvement of a minister or chaplain can be invaluable in helping patients come to terms with this suffering. When pain and symptoms are adequately controlled, the dying patient will often withdraw a request for hastened death.

In rare cases, however, aggressive treatment of pain or other end-of-life symptoms does not bring adequate relief. In these cases, and as a last resort, palliative sedation can be considered. Palliative sedation, sometimes also called terminal sedation, is the use of progressively higher levels of sedation to help relieve otherwise intractable and distressing pain at the very end of a patient's life.[23] Importantly, the purpose of palliative sedation is to relieve uncontrolled pain and suffering, not to hasten a person's death. The aim of the treatment is to achieve the lowest level of sedation that adequately relieves a patient's symptoms. Examples of conditions that could merit palliative sedation include agitated terminal delirium, intractable nausea and vomiting, uncontrollable pain, or unrelenting shortness of breath in actively dying patients who have not responded to the usual palliative treatments.

When someone is considering palliative sedation, consultation with a palliative care specialist is strongly recommended, both for guidance in the process and to ensure that all other palliative options have been fully exhausted. Full involvement of the family is encouraged unless this is contrary to the patient's wishes. The family will need continued support through the process, so the involvement of hospice and chaplaincy is also strongly recommended. If artificial nutrition and hydration are stopped at the start of palliative sedation, death will usually occur within two weeks.

5) The determination of death and considerations about organ donation

People of faith who are committed to living out Christ's command to love and serve others may also feel that donating their organs represents a concrete way to fulfill that command. Belief in the resurrection does not require that our organs disintegrate with our bodies after death. Indeed, the apostle Paul reminds us that we receive a "spiritual body," not a physical body, at the time of our resurrection.[24] So, it is a compassionate act to donate one's organs as long as doing so does not cause one's own death.

The question of when death occurs is therefore of great importance. In this regard, the "Dead Donor Rule" has been the foundation of organ donation policy and practice. This rule essentially states that organs on which a person depends for survival, such as the heart and both lungs, cannot be taken for transplantation into another person until the donor is irreversibly dead.[25] In order to insure that there are no conflicts of interest and that a donor patient is not sacrificed for the benefit of the organ recipient, the medical team caring for the donor is always kept completely separate from the transplant team. In fact, the medical care team for a potential donor will not normally even broach the subject of organ donation with the patient. Instead, a special team not involved in care will initiate those discussions with the family so as not to create even the appearance of compromised care.

Organ donation often becomes a consideration when an individual is critically injured in an accident and will not survive, is determined to have no brain activity following a severe head injury or intracranial hemorrhage, or will soon expire from a terminal condition that has not caused damage to the person's organs. If people have agreed to donate organs (often noted on their driver's license) and are determined to be dead based on neurological criteria (i.e. "brain dead"), they will be pronounced dead by a physician and then taken to an operating room while remaining on a ventilator for removal of viable, healthy organs for transplantation.[26]

Organ donation after brain death became the primary approach for organ transplantation beginning in the late 1960's. However, since the late 1990s, organ donation after the cessation of blood circulation by a non-beating heart has become the more common standard. The typical circumstance concerns a patient who is unresponsive, dependent on a ventilator for breathing, who has no hope of recovery, and is expected soon to die. If the patient, or the patient's surrogate decision-maker, has expressed the desire to donate organs and death is believed to be imminent, the individual is taken to an operating room where the ventilator is removed. The team caring for the person then waits a certain amount of time, typically no more than thirty minutes, to see if the heart stops. If the heart stops, with complete cessation of blood circulation, the physician waits another period of time (typically five minutes) to make sure that the heart does not start beating again. If the heart does not restart, the physician attending to the patient will pronounce him or her dead. The body then will be moved directly into another operating room where the person's viable organs are removed for transplant.

Death by neurological criteria ("brain death") and death by cardiovascular criteria ("donation after cardiac death") are both recognized as legal determinations of death under the Uniform Determination of Death Act, which reads, "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 brain stem, is dead. A determination of death must be made in accordance with accepted medical standards."

However, these criteria for the determination of death have not been without controversy. Persons declared dead by neurological criteria ("brain death") usually appear to have normal skin tone while on a ventilator. Their heart will continue to beat and they often appear peaceful, even though they are completely unresponsive. Thus, many family members have difficulty believing that a loved one in such a condition actually is dead. With regard to determinations made based on cardiac death, some worry that their loved one could experience a spontaneous restart of the heart, even though this has not been observed when more than one minute has passed after cessation of blood circulation without cardiac

activity (which is why various protocols for controlled cardiac donation recommend a waiting period of between two and five minutes). In some institutions, the waiting time has been shortened from five minutes in the interest of retrieving viable organs, since the longer the waiting period, the more likely an organ will degrade and lose viability for a transplant recipient.

The authors of this document encourage consideration of organ donation by all Presbyterians. It is truly a gift of life to those awaiting an organ. If death is expected and organ donation desired, it is reasonable to allow medical professionals to take all ethically acceptable measures to retrieve organs that will be viable for transplantation. It is also essential to do everything appropriate to insure the comfort and dignity of the dying patient donor and to insure that the life of the patient is not sacrificed to benefit another person. With these safeguards, life is given to one, but not taken from the other. This is truly a gracious act.

6) Pastoral care of persons seeking physician aid in dying

The Christian faith has a presumption toward life and understands the fulfillment of each person's life to be found in the love and service of God and neighbor. When our callings appear blocked by the extremes of depression, isolation, chronic pain, severe disability or degenerative disease, we may question God's care and our own capacity to contribute to life. Then, sometimes in resignation, anger, grief, or to spare others the burden of our dependence, we may consider ending our lives. For some whose incapacity is advanced and pain seems unbearable and untreatable, new laws in several states allowing physician aid-in-dying (PAD)—also referred to by many as physician-assisted suicide (PAS)—may seem to promise deliverance or "death with dignity." These laws, within certain restrictions, allow a competent, terminally ill, adult patient to request and receive from her or his physician a prescription for medication (usually barbiturates) that is sufficient to produce unconsciousness and then death. While Presbyterians hold many views on the legalization of PAD, and while the PCUSA has not taken a position in opposition to such

legalization, pastoral and communal support of persons considering PAD needs to take into consideration a number of important factors.

In the above discussion of palliative sedation, it is noted that there may be a point at which an individual's pain is not manageable except by inducing some level of unconsciousness. By medically inducing a state of anesthesia, suffering is relieved. Additionally, the U.S Supreme Court has already affirmed the legality of withdrawing artificial feeding and other life-support technologies, leading to death by 'natural' causes or processes. Finally, it is often said that hospice programs have turned pain control in dying patients into an art form and that there is hardly any pain that is uncontrollable. Given all of these options, many wonder why there is so much interest in legalizing PAD.

The availability of PAD indeed may allow patients to end pain and suffering or to avoid greater physical and mental deterioration. At the same time, however, experience in Oregon, the first U.S. state to legalize PAD, has shown that the majority of patients who request, receive, and actually use the lethal drugs do not do so because of unbearable physical pain, but in response to a different kind of anxiety or suffering. They employ PAD as a means of retaining (or regaining) some sense of control in an otherwise uncontrollable situation. PAD gives patients greater control over the timing of death because they choose when to swallow the medications that will cause death. While they cannot change the fact that they are terminally ill, these patients appear to highly value the ability to make choices about the timing and ease of their deaths.

It is important to note that even where it is legal, there are restrictions on PAD. Patients who wish to use this option sometimes wait too long, often anticipating one last visit from a loved one, and become unable to swallow the lethal medications without assistance. But if either the prescribing physician or a family member administers the medication, their action would fall into the category of active euthanasia ("mercy killing"), which is illegal in all fifty states.

As noted above, our Reformed tradition does not teach us to see pain and suffering as either redemptive or as some sort of

just punishment, and we do not assume or project divine judgment on those who may hasten the end of their lives. Yet our tradition does emphasize the central theological significance of our interconnectedness, our relationships, and our covenants with one another and with God. To paraphrase the poet John Donne, "No one is an island," and as Christians we are our "brothers' and sisters' keepers." We recognize that each death diminishes us as a human community, but we have a positive responsibility to contribute to God's healing whenever we can—even when that healing is not a cure, but a grace-filled conclusion.

For those ministering to persons who are seeking PAD for themselves, at least two theological concerns present themselves: 1) that the practice of PAD may encourage or reinforce isolation of the individual patient from community; and 2) that the potential exists for understanding one's life or one's body as a possession to be kept or disposed of rather than the gift of a gracious God. Precisely because we trust in a loving God who came "not to condemn the world, but in order that the world might be saved,"[27] we do not condemn those who choose to die. We understand that a sense of damnation may well characterize the feelings of some who choose to end their lives, and we understand the Gospel as God's hand—Christ's body—ever stretched out to hold us, even to hold us back from self-destruction. Thus we, as a church, pray that each person *in extremis*, in a "dark night of the soul," be empowered to cling to life even after the deepest tragedies and sadness.

Yet the choices of a severely ill person facing a terminal diagnosis are spiritual, emotional, and physical. The pastor should attempt to promote the fullest possible involvement of the family and congregation in supporting the patient in making decisions consistent with the patient's lived experience and conscience. If it is indeed consistent with the values and beliefs of the dying patient, if the kinds of goodbyes and closings that they seek can be better accomplished, then the option of PAD might possibly be justified and done with reverence and even thanksgiving.

The role of the physician in end-of-life care should not be characterized as "playing God," either in assisting the

prolongation of life or allowing its cessation. In either case, health professionals can be seen as assisting God in the work of caring for us and bearing with us the burdens of bodily existence. This burden sharing is consistent with an incarnational theology. To be a patient is often to submit, to receive, and endure a loss of powers that feels like dispossession and may be accompanied by other feelings of abandonment. So some people may conceive of the physician or even medical interventions themselves as an empowering deliverer or a cruel jailor. While that thinking borders on idolatry, it is *we* who are magnifying the professionals' role. They are not usurping God's role.

The second theological concern about understanding the body or life as a possession we control also represents an important consideration with respect to PAD. The old expression, "get right with God," which can include the reconciliation with and forgiveness of family members and others, may be understood here as a preparation to "let go and let God" receive our spirits. Our pain or suffering may make it hard for us to pray or worship, or even to have visitors. Or we may be only intermittently conscious, and we may see ourselves increasingly falling away from the person we understood ourselves to be. God, who knows us better than we know ourselves, understands this process and calls doctors and other caregivers to accompany us on a journey. For Christians, however, this journey does not end with dying. While family, friends, pastoral leaders, and medical providers help us to the precipice of death, the next step on that journey beyond death is something with which no human can assist. At that point, we are lifted up into the communion of saints and the presence of Christ, an abiding presence from the beginning of life and beyond death.

The following pages contain the resolution framework, as approved by the 222nd General Assembly of the Presbyterian Church (U.S.A.).

GENERAL ASSEMBLY RECOMMENDATIONS ON "ABIDING PRESENCE: LIVING FAITHFULLY IN END-OF-LIFE DECISIONS"

In fulfillment of the direction of 221st General Assembly (2014), the Advisory Committee on Social Witness Policy recommends that 222nd General Assembly (2016) do the following:

1) **Approve the pastoral guidebook, "Abiding Presence: Living Faithfully in End-of-Life Decisions," as a theologically and ethically grounded resource for pastoral care in light of new medical and legal choices involving the prolongation or cessation of life, to be made available through appropriate electronic and print means;**
2) **Approve the affirmation and recommendations following for Christian public witness in support of the advance care planning, healthcare access, and respect for personal conscience described in the guidebook;**
3) **Encourage Presbyterian medical personnel, care-givers, pastors, deacons, and other providers of end-of-life treatment, care, and support to lead studies and discussions of these resources on a regular basis within their congregations and communities to strengthen the understanding and use of advance directives.**

Affirmation: Faithful Living at the End-of-Life

God's good gift of life does not come without God's guidance, guidance carried in the scriptures of Old and New Testaments and interpreted in our Confessions of Faith. As medical science has reduced pain and permitted longer life through the discovery of countless new therapies and treatments, the duration and enjoyment of human life have been extended for literally billions of people. Our conviction of God's abiding presence has accompanied this process, deepened by our Reformed Christian appreciation for the role of science in healing, and our pastoral sense that our wholeness in Christ co-exists within the—sometimes tragic-- range of human limitations. The sacredness of life reflects its cosmic Giver; as part of the web of creation, we accept the goodness of our inspirited bodies alongside their fragility, aging, and inevitable

death. We cherish the conviction of God's embrace in life, through and beyond death— vividly expressed in St. Paul's understanding of the resurrection in I Corinthians 15—but we also recognize that death is a mystery, and often still a time of pain and suffering.

The Reformed tradition as we understand it sees death as part of a purposeful journey that is undertaken by each of us in community, such that our baptisms are recalled and completed at our deaths, whether they be sudden and untimely, prolonged and painful or long-expected and peaceful. The meaningfulness of our lives is not determined by their duration but by their connection to the One who loves us and rejoices and suffers with us. Our lives are not our own to dispose of; even pain-wracked and frail bodies are basic to who we are as God's children and deserve respect in all stages of life and in all funeral arrangements. Death is not to be denied, hidden, or feared, as we believe its power to separate us from the love of God has been ended. Thus through grace we die "in the Lord," and by faith in God's cosmic purpose, we look toward the redemption of all things and the "wiping away of every tear."

This theological/spiritual/ethical context must be considered in advance care planning. All of the stakeholders in end-of-life planning and care bring their spiritual and moral convictions to the challenges explored in *Abiding Presence*. All of the community members who should or could take responsibility for the care of the dying bring values, principles, beliefs, and virtues to advance care planning. Not only do doctors, nurses, social workers, chaplains, hospice staff members, therapists, pastors, Stephen Ministers, family members and patients have spiritual convictions, conscientious concerns, and ethical standards, they function in hospitals, hospices, religious and professional communities, and other institutions that at best will foster cultures of compassion and commitments to caring. Clinical ethicists in hospitals, hospital ethics committees, and chaplains can play a role facilitating conversations about shared and possibly competing values, principles, and laws.

It is important to note the progression of care as illness progresses. Critical care (full life-saving care toward health restoration), may then include palliative care (a multidisciplinary approach to supporting the personhood of the patient) that can co-exist with critical care, and continue if the decision to discontinue critical care is made. Finally, hospice care discontinues dimensions of critical

care, while enhancing care of mind, body, and soul, through the end-of-life journey.

Decisions to hasten death may be understandable as a last resort when all connection to one's community has been or will be lost and medical pain management is no longer effective. Both medically and spiritually, it is always crucial that the Church and individual Christians address the reasons why people choose to end their lives, listening and drawing on God's love as best we can, and avoiding condemnation. While sharing in the historic Christian opposition to suicide, we do not find it condemned in scripture nor see ourselves called to judge others, particularly those facing irreversible deterioration of awareness and bodily function. A separate issue is the use of deep sedation at the end of a person's life to control severe pain. Such sedation invokes a law of double effect: pain control may increasingly suppress bodily function. The ethical concern here is the intent of the medication, either to assist with pain control, or to hasten death. Pain management may in some cases be chosen prayerfully and within one's fully informed circle of care, knowing that death is typically a by-product at some point.

Death for us is not simply an individual event in a natural process, but a communal leave-taking still connected to God that involves our family, friends, and congregation. We grieve, but not as those without hope. Through God's redemptive love in Christ, seen and heard and felt in our traditions of worship and prayer, we know this: "For if we have been united with him in a death like his, we shall certainly be united with him in a resurrection like his" (Romans 6:5). This theological framework prompts us to put end-of-life planning alongside planning for funerals, wills, and final communications to our loved ones of our gratitude, blessings, learnings, and prayers for the future.

The Church has provided resources on medical efforts to manage the uncertainty and pain of death since 1974, addressing first the "artificial prolongation" of human life, and then addressing efforts at shortening or ending lives seen to have grown unbearable or unresponsive. The current handbook for approaching the newest array of end-of-life treatments builds upon the church's earlier efforts (outlined in the background section to this resolution). The

recommendations below are designed to help ensure a proper context for wise end-of-life decision making.

(Recommendations Concerning Advance Care Planning and End of Life Choices)

In order to support persons facing end-of-life decisions, the 222nd General Assembly (2016) of the Presbyterian Church (U.S.A.):

a. **Encourages all members and friends active in the denomination to develop their own end-of-life directives, surrogate decision-makers, "living wills," durable powers of attorney for health care, Physician Orders for Life-Sustaining Treatment (POLSTs), or other vehicles recognized by their states, to guide their treatment in the case of incapacity and/or irreversible medical decline. Copies of these documents should be shared with both primary and secondary (fallback) persons selected to carry the power of making health care decisions when one is unable to do so oneself. Furthermore, it is very illuminating to discuss one's end of life values and preferences with the range of family members, physicians, nurses, and congregational care providers.**

b. **Affirms the value of discussions between patients and their physicians, family members, ministers/chaplains/other pastoral care givers, social workers, and hospice personnel, and affirms the inclusion of appropriate reimbursement by private and public healthcare insurers, such as state and national networks developed under the Affordable Care Act. Such advocacy—which "Abiding Presence" may directly assist—is part of "the distribution of the best health care for all people regardless of race, gender, or economic standing." This confirms the goal of the 1983 General Assembly in the "Covenant of Life and the Caring Community," in light of advances in pain management and palliative care through both hospital and hospice programs.**

c. **Affirms the judicial and legislative precedents of the U.S. Supreme Court's Cruzan decision and the Patient Self-Determination Act (both in 1990) that protect the rights of competent individuals (or their designated representatives) to refuse all life-prolonging medication, hydration, and/or**

nutrition, and enjoins healthcare facilities to provide guidance for each patient to have advance directives for medical treatment.

d. Recognizes the diversity of theological and ethical positions among Presbyterians regarding legalization of PAD (physician aid-in-dying), and calls upon those states legalizing PAD to research and carefully regulate the law's effects upon persons with intellectual and developmental disabilities (IDD) and those who are socially, economically, emotionally and psychologically vulnerable. Also, all states should enhance the scope of end-of-life *choices* by enacting public policies that will increase and sustain the quality and availability of palliative care, hospice care, and long-term care. It is affirmed that the patient is the moral agent in these circumstances with appropriate safeguards to insure that the patient is not mentally ill or coerced. This position is based on the Reformed affirmation of the "freedom of Christian conscience" and caution against implicit assumptions that death is always preferable to extreme suffering.[28]

e. Supports careful studies of the range of impacts of PAS or aid-in-dying laws, funded by appropriate federal and state authorities, and including perspectives of nurses, religious care-givers, and family members (frequently female) who may be present at death.[29] Any in-depth theological and ecumenical study of PAS would be wise to consider enduring medical-ethical traditions,[30] including those of nursing; disparities among state and federal laws/regulations and health insurance provisions; and the impact of PAS on palliative care, which is not limited to terminal and/or hospice situations.

f. Encourages organ donation as a way to share a very gracious gift and as a commitment that can be part of one's advance directives.

g. Encourages the careful planning of funerals, burials, and cremation, in ways that celebrate the resurrection and presence of God, honor the bodies we have been given, and remember the individual in community. Congregations are encouraged to provide worship resources for advance planning in this area,

particularly if they also maintain columbaria or cemeteries on their properties.

Rationale in the form of a handbook for caregivers:

The handbook approved by the 222nd General Assembly of the Presbyterian Church (U.S.A.) may be found earlier, beginning on page 1 of this publication.

The Appendices for the original report may be found online:

APPENDIX A: Background: Previous Presbyterian Studies Regarding End-of-life Care and Decisions

APPENDIX B: Background: Historical Ethical and Legal Context for End-of-life Decision Making in American Culture

APPENDIX C: Suggested Reading

The Advisory Committee on Social Witness Policy (ACSWP)

www.pcusa.org/acswp or

www.presbyterianmission.org/ministries/acswp

Endnotes

[1] Rom. 8:38-39
[2] Rom. 14:8
[3] Philip A. Pizzo, "The Doctor: For Life and at the End of Life," Annals of Internal Medicine 162, no. 3 (2015): 228.
[4] Institute of Medicine (IOM). Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life (Washington, DC: The National Academics Press, 2015).
[5] Katy Butler, Knocking on Heaven's Door: The Path to a Better Way of Death, (New York: Scribner, 2013).
[6] Elizabeth B. Lamont and Nicholas A. Christakis, "Prognostic Disclosure to Patients with Cancer near the End of Life," Annals of Internal Medicine 134, no. 12 (2001): 1102.
[7] United States Agency for Healthcare Research and Quality, Advance Care Planning: Preferences at the End of Life, (USAHRQ, 2003).
[8] David I. Shalowitz, Elizabeth Garrett-Mayer, and David Wendler, "The Accuracy of Surrogate Decision Makers: A Systematic Review," Archives of Internal Medicine, 166, no. 5, 2006: 493-497.
[9] James M. Gustafson, Ethics from a Theocentric Perspective, Vol. I: Theology and Ethics (Chicago: University of Chicago Press, 1981).
[10] The latter suggests that life has an innate or "natural" trajectory.
[11] Karl Barth, Church Dogmatics (Louisville, KY: Westminster John Knox Press, 1994), 194.
[12] For a fuller discussion of these norms, see Presbyterian Church in the United States, The Nature and Value of Human Life (The 121st General Assembly, 1981).
[13] All names are pseudonyms.
[14] 1 Thess. 4:13
[15] Formerly known as the Joint Commission on the Accreditation of Healthcare Organizations.
[16] Abigail Rian Evans, "Healing in the Midst of Dying: A Collaborative Approach to End of life Care," in Living Well and Dying Faithfully: Christian Practices for End of life Care, ed. John Swinton and Richard Payne (Grand Rapids, MI: William B. Eerdmans Publishing Company, 2009), 178.
[17] International Federation of Social Workers, "Global Definition of Social Work," 2014, http://ifsw.org/get-involved/global-definition-of-social-work.
[18] See the Federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

[19] Presbyterian Church in the United States, *The Nature and Value of Human Life* (The 121st General Assembly, 1981), 5

[20] Amy Platinga Pauw, "Dying Well" in *Living Well and Dying Faithfully: Christian Practices for End of Life Care*, ed. John Swinton and Richard Payne (Grand Rapids, MI: William B. Eerdmans Publishing Company, 2009), 18.

[21] Gen. 1:26

[22] Paul L. Lehmann, *Ethics in a Christian Context* (New York: Harper and Row, 1963), 122.

[23] Timothy E. Quill, Bernard Lo, Dan W. Brock, and Alan Meisel, "Last Resort Options for Palliative Sedation," *Annals of Internal Medicine* 151, no. 6, 2009: 421-424; Nigel Sykes and Andrew Thorns, "Sedative Use in the Last Week of Life and the Implications for End of Life Decision-making," *Archives of Internal Medicine* 163, no. 3, 2003: 341-344; Timothy E. Quill, Ira R. Byock, and the ACP-ASIM End of Life care Consensus Panel, "Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids," *Annals of Internal Medicine* 132, no. 5, 2000: 408-414; American Academy of Hospice and Palliative Medicine, *Primer of Palliative Care, 6th Edition* (American Academy of Hospice and Palliative Medicine, 2014).

[24] 1 Cor. 15: 44

[25] One kidney can be taken from living donor because that person can survive on the other kidney alone.

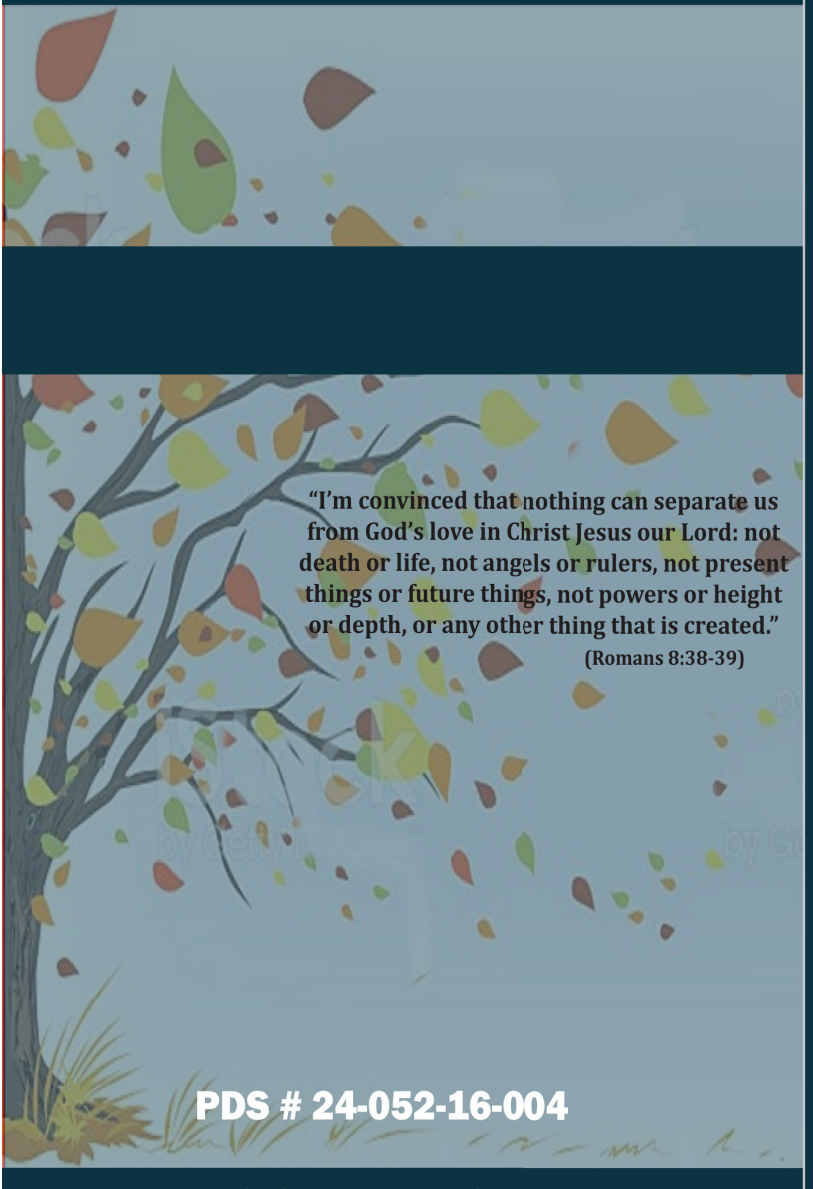
[26] The numbers of persons requiring an organ transplant for survival or to live a life free of the burden of dialysis (in the case of kidneys) far exceeds the number of organs available for transplant.

[27] John 3:17

[28]In addition to the current guide, *Abiding Presence*, the Presbyterian resource, "In Life and in Death We Belong to God: Euthanasia, Assisted Suicide, and End-of-Life Issues (1995)," has provided a way to study these issues in adult study format that is consistent with this resolution's position.

[29]This is to recognize that withdrawing life support and terminal sedation are not PAS, and that laws which allow a physician to prescribe a death-inducing drug may also restrict the role of anyone other than the patient in administering such a drug. The approach in *Abiding Presence* would caution against any legal provision that might enforce an isolation of the patient that challenges our Christian approach to care-giving and community.

[30]This affirmation, the recommendations, and the resource for those facing end-of-life decisions honor those traditions of ethical care by the several medical disciplines. These documents do not provide specifically legal advice and a disclaimer to that effect will be provided in any posted or printed versions.



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