REPORT OF THE JOINT COMMISSION ON HEALTH CARE

ADVANCED DIRECTIVES STUDY PURSUANT TO HJR 603

TO THE GOVERNOR AND THE GENERAL ASSEMBLY OF VIRGINIA



HOUSE DOCUMENT NO. 75

COMMONWEALTH OF VIRGINIA RICHMOND 2000

.

JOINT COMMISSION ON HEALTH CARE

Chairman The Honorable Kenneth R. Melvin

Vice Chairman The Honorable Jane H. Woods

The Honorable William T. Bolling The Honorable Joseph V. Gartlan, Jr. The Honorable Benjamin J. Lambert, III The Honorable Stephen H. Martin The Honorable Edward L. Schrock The Honorable Edward L. Schrock The Honorable Stanley C. Walker The Honorable Thomas G. Baker, Jr. The Honorable Thomas G. Baker, Jr. The Honorable Bobert H. Brink The Honorable John J. Davies, III The Honorable John J. Davies, III The Honorable Jay W. DeBoer The Honorable Alan A. Diamonstein The Honorable Franklin P. Hall The Honorable Phillip A. Hamilton The Honorable Harvey B. Morgan

Secretary of Health and Human Resources The Honorable Claude A. Allen

> **Executive Director** Patrick W. Finnerty



.

. . .

.

Preface

House Joint Resolution No. 603 of the 1999 General Assembly Session (Appendix A) directs the Joint Commission on Health Care (JCHC) to study the use of advance directives in the Commonwealth. As part of this review, JCHC is required to examine (1) the percentage and categories of persons who utilize advance directives and methods to increase that number; (2) legal or ethical obstacles which inhibit the provisions of an advance directive; (3) methods which would better inform health care practitioners about the existence of advance directives; and (4) methods to insure portability and reciprocity for advance directives among health care providers and institutions as well as other states.

Based on our research and analysis during this review, we concluded the following:

- there are two general types of advance directives a living will and a durable power of attorney for health care;
- advance directives offer several potential benefits, such as helping to impose order on situations surrounding the need to make health care decisions near the end of an individual's life or following a major trauma;
- advance directives also have their limitations, including the possibility that undue reliance will be placed on the written document at the expense of ongoing communication between patient and physician;
- a survey by JCHC staff found relatively low utilization of advance directives in Virginia in that thirty-four percent of hospitals and nursing homes reported that fewer than 20 percent of their patients and/or residents have an advance directive;
- public misperceptions (i.e. that they will result in total medical abandonment with no provisions of comfort care) are a major barrier to greater utilization;
- a lack of sufficient awareness among health care practitioners (i.e. concerning the most appropriate method to help a patient complete an advance directive) is another barrier;
- there are numerous potential obstacles to honoring advance directives (i.e. an individual's family members may be opposed to his or her expressed wishes);
- there is some disagreement concerning the extent to which advance directives are honored by health care practitioners but 60 percent of the respondents to the JCHC survey did not perceive problems with honoring advance directives;

- varying statutory provisions among Virginia and surrounding states (i.e. pertaining to required notarization) raise some concerns about the portability of advance directives between health care settings; and
- 85 percent of JCHC survey respondents believe that the state should do more, through education and outreach initiatives, to promote increased utilization of advance directives.

A number of policy options were offered for consideration by the Joint Commission on Health Care regarding the issues discussed in this report. These policy options are listed on pages 39-40.

Our review process on this topic included an initial staff briefing, which comprises the body of this report. This was followed by a public comment period during which time interested parties forwarded written comments to us regarding the report. The public comments (attached at Appendix <u>D</u>) provide additional insight into the various issues covered in this report.

On behalf of the Joint Commission on Health Care and its staff, I would like to thank the Virginia Board of Medicine, the Medical Society of Virginia, the Virginia Hospital and Healthcare Association, the Virginia Health Care Association, the Virginia State Bar, and the Virginia Bar Association for their cooperation and assistance during this study.

Patrick W. Finnerty Executive Director

December, 1999

TABLE OF CONTENTS

I.	AUTHORITY FO	R THE STUDY	1	
Π.	OVERVIEW OF A	ADVANCE DIRECTIVES	1	
III.	UTILIZATION O	F ADVANCE DIRECTIVES	7	
IV.		NCREASE AND IMPROVE ND ACCEPTANCE OF ECTIVES	19	
V.	POLICY OPTIONS			
VI.	APPENDICES			
	Appendix A:	House Joint Resolution 603		
	Appendix B:	Suggested Form of Written Advance Directive, Section 54.1-2984, CODE OF VIRGINIA		
	Appendix C:	Selected Definitions from Virginia Health Care Decisions Act, Section 54.1-2982, CODE OF VIRGINIA	·	
	Appendix D:	Summary of Public Comments		

.

.

I. Authority for the Study

House Joint Resolution No. 603 of the 1999 General Assembly Session (Appendix A) directs the Joint Commission on Health Care (JCHC) to study the use of advance directives in the Commonwealth. As part of this review, JCHC is required to examine (1) the percentage and categories of persons who utilize advance directives and methods to increase that number; (2) legal or ethical obstacles which inhibit the provisions of an advance directive; (3) methods which would better inform health care practitioners about the existence of advance directives; and (4) methods to insure portability and reciprocity for advance directives among health care providers and institutions as well as other states.

Issue Brief Outline

This issue brief presents the results of JCHC's staff review as directed by HJR 603. This issue brief is divided into five sections. This section discussed the authority for the study. The second section provides a general overview of advance directives, including provisions of the Virginia Health Care Decisions Act and the federal Patient Self-Determination Act. The third section examines the extent to which advance directives have been utilized across the country and in Virginia, and discusses potential obstacles to their utilization and implementation. The fourth section considers various methods to increase utilization and acceptance of advance directives on the part of the general public and health care practitioners. The fifth section discusses policy options.

II.

Overview of Advance Directives

An Advance Health Care Directive Is A Means By Which An Individual Can Express His Wishes Concerning Medical Treatment, or By Which Another Person Can Be Empowered To Make Health Care Decisions on His Behalf

There are two general types of advance directives. A living will is an instrument, usually a written document, by which an individual typically seeks to direct the course of health care in the event of an emergency or end-of-life situation. A living will also is often used by individuals in an attempt to customize the parameters of their medical care in advance in the event they are unable to do so, by reason of incapacity, at some later date. Oftentimes, the primary purpose of a living will is to seek to prevent the application of life prolonging procedures that would serve only to artificially prolong the dying process. A durable power of attorney for health care is the second major type of advance directive. This is a means by which an individual may appoint an agent to make health care decisions on his behalf, should he become incapable of making an informed decision at some point in the future.

The Virginia Health Care Decisions Act Establishes The Procedure for Making an Advance Directive in the Commonwealth

The Virginia Health Care Decisions Act (HCDA) is contained in §54.1-2981 et seq. of the *Code of Virginia*. The HCDA defines an advance directive as either (1) a voluntarily executed, witnessed written document, or (2) a witnessed oral statement, made subsequent to the time that the individual is diagnosed as suffering from a terminal condition. The HCDA establishes the procedure that must be followed in order for an advance directive to be lawfully executed. Section 54.1-2983 of the *Code of Virginia* states that:

Any competent adult may, at any time, make a written advance directive authorizing the providing, withholding, or withdrawal of life-prolonging procedures in the event such person should have a terminal condition. A written advance directive may also appoint an agent to make health care decisions for the declarant under the circumstances stated in the advance directive if the declarant should be determined to be incapable of making an informed decision. A written advance directive shall be signed by the declarant in the presence of two subscribing witnesses.

Section 54.1-2983 of the *Code of Virginia* also authorizes a procedure for executing an oral advance directive. The procedure is generally the same as for an written advance directive, except that it "shall be made in the presence of the attending physician and two witnesses". The terms "incapable of making an informed decision," "life-prolonging procedure," and "terminal condition" are defined in §54.1-2982 of the *Code of Virginia*. (Appendix B).

The HCDA specifies that it is the individual's responsibility to "provide for notification to his attending physician that an advance directive has been made." In the event that the individual is incapable of communication, any other person may notify the attending physician.

Once notified, the attending physician is required to "promptly make the advance directive or a copy of the advance directive, if written, or the fact of the advance directive, if oral, a part of the declarant's medical records."

Section 54.1-2984 of the *Code of Virginia* provides a suggested, nonmandatory form for a written advance directive (Appendix C). So long as an individual complies with the provisions of §§ 54.1-2982 and 54.1-2983, an individual may utilize any type of advance directive format he or she desires. There are three components to the suggested form: a living will, a durable power of attorney for health care, and appointment of an agent to make an anatomical gift. In utilizing the suggested format, an individual may make use of any or all of the three component sections.

Section 54.1-2985 of the *Code of Virginia* states that an advance directive may be revoked at any time by the declarant. This may be done by (1) a signed, dated writing, (2) physical cancellation or destruction of the advance directive by the declarant or by another in his presence and at his direction; or (3) oral expression of intent to revoke. According to the statute, "any such revocation shall become effective when communicated to the attending physician."

The Federal Patient Self Determination Act (PSDA) Requires Specified Health Care Facilities to Provide Information Concerning An Individual's Right to Execute An Advance Directive

The PSDA, enacted by Congress in 1990, marked the beginning of an effort by the federal government to increase public awareness and utilization of advance directives. The PSDA requires hospitals, skilled nursing facilities, hospice programs, home health agencies, and health maintenance organizations that participate in the Medicare and Medicaid programs to:

- provide patients with written information about their rights under state law to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives;
- provide patients with written information about the policies of the provider or organization respecting the implementation of such rights;
- document in a prominent part of the individual's current medical record whether or not the individual has executed an advance directive;

- not to condition the provision of care or otherwise discriminate against the individual based on whether or not he or she has executed an advance directive;
- ensure compliance with the requirements of state law respecting advance directives at facilities of the provider or organization; and
- provide for education for staff and the community on issues concerning advance directives.

The United States Health Care Financing Administration (HCFA) subsequently promulgated regulations pursuant to the PSDA. The regulations specify that each state, acting through a state agency, association, or other private non-profit entity, develop a written description of the state law concerning advance directives to be distributed by Medicaid providers and health maintenance organizations.

There Are Several Other Types of Regulations and Standards Designed to Ensure That Health Care Facilities Focus on Advance Directives

In addition to the PSDA, there are other rules applicable to health care providers which are indicative of the importance that has been placed on advance directives. For example, Virginia regulations for the licensure of nursing facilities require that advance directives, if known, must be included in the complete medical plan of care developed for each resident. Advance directives are also required to be included in the initial and periodic assessment of each resident's needs.

Hospital accreditation standards developed by the Joint Commission for Accreditation of Health Care Organizations (JCAHO) require that hospitals address advance directives. The intent of this standard is for a hospital to (1) determine whether a patient has or wishes to make an advance directive, (2) provide assistance to patients who wish to formulate an advance directive, and (3) ensure that health care professionals and designated representatives honor the directives within the limits of the law and the hospital's mission, philosophy, and capabilities.

HCFA promulgated new regulations in 1999 which established a new patients' rights condition of participation that hospitals must meet for the Medicare and Medicaid programs. One of the new standards established as part of the patient's rights condition of participation is "exercise of rights." According to the standard, the patient has the right to participate in the development and implementation of his or her plan of care. According to the regulations, this includes the patient having "the right to formulate advance directives and to have hospital staff and practitioners who provide care in the hospital comply with these directives."

The *Code of Virginia* Authorizes the Use of Durable Do-Not-Resuscitate Orders

Section 54.1-2987.1 of the *Code of Virginia* authorizes the issuance of a durable do not resuscitate order (DDNR) by a physician to his patient, with the patient's consent. Pursuant to a DDNR, measures such as cardiopulmonary resuscitation, endotracheal intubation, artificial ventilation and defibrillation are be withheld or withdrawn. A DDNR is valid indefinitely unless revoked by the patient, and it is completely portable among all health care facilities and settings. A DDNR is different from other types of do-not-resuscitate orders that may be issued by a physician, but which are not portable to different health care settings.

A DDNR is different from an advance directive, since it is an actual physician's order. A DDNR may be issued by a physician to implement an individual's wishes as expressed in an advance directive. However, it is not necessary for an individual to have an advance directive in order to be issued a DDNR. In addition, while only a competent adult may execute an advance directive, DDNR orders may be entered for children or for other individuals who have lost decision making capacity.

The Health Care Decisions Act Provides Immunity from Liability Associated With Honoring the Provisions of an Advance Directive

Section 54.1-2988 of the *Code of Virginia* states that "A health care facility, physician or other person acting under the direction of a physician shall not be subject to criminal prosecution or civil liability or be deemed to have engaged in unprofessional conduct as a result of issuing a Durable Do Not Resuscitate Order or the withholding or withdrawal of lifeprolonging procedures under authorization or consent obtained in accordance with this article." The statute also states that no person or facility providing, withholding, or withdrawing treatment, or a physician issuing a DDNR, "shall incur liability arising out of a claim to the extent the claim is based on lack of authorization or consent for such action." According to the statute, all of these provisions shall apply unless it is shown "by a preponderance of the evidence" that a person did not in good faith comply with statutory provisions.

x

•

III. Utilization of Advance Directives

There Are Several Potential Benefits That Can Result from the Use of Advance Directives, But They Also Have Their Limitations

Advance directives are often credited by medical and legal professionals, and by others in the health care arena, with helping to impose order on situations surrounding the need to make health care decisions near the end of an individual's life, or following a major trauma. To the extent that an advance directive prevents the burden of decisionmaking from being placed on family members, during what can be a crisis-like situation, advance directives can be invaluable. During the study, several individuals – including attorneys, physicians, and advocates for aging - described the need for advance directives. For example:

The need for advance directives is critical. If you are unable to speak for yourself, you need your wishes to be carried out. If you have specific wishes, a written advance directive provides you with a better chance that those wishes will actually be carried out.

* * *

Advance directives are utterly, completely essential. Many individuals outlive their relatives, become estranged from their families, or lead alternative lifestyles. Consequently, the person who is in the best position to make a decision for someone else often has, without a written advance directive, no legal authority to make the decision. People are allowed to lie around and suffer, because there is no one empowered or willing to make a decision.

* * *

There is a tremendous potential downside to not having a health care proxy. This includes under treatment for pain, as well as overly aggressive treatment. It also places a burden on family members who do not have enough information about your wishes for end of life care.

The general view among this school of thought is that, without an advance directive, there is an increased likelihood that an individual's family members will have contentious disputes concerning the plan of care, and that health care providers and medical professionals will be caught in the middle of these episodes. This is believed to be the case even though, in all likelihood, an advance directive will never actually be needed. As one attorney stated:

Ninety-five percent of the time, having a written advance directive is not essential. In most cases, family members will be aware of what the individual's wishes are, and will be supportive of honoring those wishes. But in the other five percent of cases, having a written advance directive can make a big difference.

However, there are other medical and legal professionals who express more caution concerning the use of advance directives, and who readily cite the limitations of these documents. While such individuals are very supportive of the need for advance planning for health care decisions, they are concerned that advance directives be properly viewed as a means to initiate advance planning, and not as an end in and of itself. One attorney and one physician stated as follows:

Advance directives are not as useful as people think. They tend to be oversold. Less emphasis should be placed on the form and more should be put on advance planning. The thinking behind the form is more important than the form itself.

Advance directives are at best a compromise between the ideal and nothing. The ideal is a conversation between the primary care provider, family, and patient. Advance directives should serve primarily as a means for starting up a conversation. They should not be viewed as just some document, because then you lose sight of their main purpose.

One definition of advance planning requires that patients:

- learn about their overall medical condition;
- understand the consequences of treatment under the given condition;
- apply the information to their personal calculus of benefits and burdens to formulate broad goals for medical care;
- become familiar with their overall state of health in the absence of any new, acute problems, not merely with their likely trajectory over the ensuring months or years but also with what the experience of illness and treatment would be like for them, and;

• articulate general goals for treatment to serve as guidelines for treatment when illness develops, not as specific directives.

Some professionals who support the use of advance directives favor the health care power of attorney version as opposed to the living will. Such individuals point out the difficulty of predicting far in advance what someone's specific wishes will be for end-of-life care. According to this view, there are too many unknown variables concerning available medical treatments and a patient's future medical condition that may influence those wishes. On the other hand, if an individual is alone at the end of life, with no friends or family members to designate as an agent using a health care power of attorney, a living will could be the only practical means of executing an advance directive.

Research Has Suggested That the Utilization of Advance Directives Is Fairly Limited

The body of available research indicates that, despite widespread interest in advance directives, only a relatively small percentage of people have actually completed one. Several studies completed soon after enactment and implementation of the PSDA provided evidence that advance directives were not widely used. A number of these studies were cited in a 1995 report by the United States General Accounting Office titled <u>Patient Self Determination Act – Providers Offer Information on Advance Directives But Effectiveness Uncertain</u>. These studies also indicated that a greater number of individuals were aware of the availability of advance directives than had actually executed one (Figure 1).

More recently, a 1999 study sponsored by the New Hampshire Partnership for End-of-Life Care reviewed 812 medical charts submitted by 64 hospitals, nursing homes, and hospice/home care agencies. The study found that 50 percent of the decedents had a living will, and 57 percent had a durable power of attorney for health care. The study concluded that the typical profile of a decedent with either a living will or a durable power of attorney for health care was widowed, over 75 years of age, with a child as the next-of-kin, and Medicare as the primary insurer.

The New Hampshire study also examined the medical charts for the prevalence of do-not-resuscitate, do-not-intubate, and do-not-hospitalize orders. The study found that:

- 1) 87 percent had a do-not-resuscitate order,
- 2) 30 percent had a do-not-intubate order, and
- 3) 8 percent had a do-not-hospitalize order.

Figure 1							
Selected Surveys of Advance Directives Awareness and Completion Rates							
Population Surveyed	Awareness Rate	Completion Rate					
Over 3,000 severely ill patients	Living will – 62% HCPA – 42%	Advance directive – 20%					
1,500 patient charts at hospitals, nursing facilities, and home health agencies	Advance directive- 67%	Advance directive – 21%					
191 nursing home residents	Living will – 87% HCPA – 82%	Living will – 18% HCPA – 48%					
46 inpatients, 50 outpatients	Advance directive - 77%	Advance directive - 29%					
116 home care patients and caregivers	Living will – 33% HCPA – 60%	Living will – 5% HCPA – 50%					
405 outpatients and 102 members of general public	Advance directive – 90%	Advance directive - 15% to 18%					
97 elderly inpatients	HCPA - 62%	HCPA - 16%					

Two Studies Conducted in Virginia Found Evidence of Fairly Low Rates of Advance Directive Utilization

A 1994 study by the Center for Biomedical Ethics and the Center for Survey Research at the University of Virginia (UVA) estimated that 20 percent of adult Virginians had living wills. The study concluded that this percentage was about the same as the percentage of adults nationwide that had living wills. The UVA study was based on the results of a telephone survey of 503 respondents. The UVA study did find that there were important differences in the utilization of living wills among subgroups of the population, especially in terms of race, economic status, and religion (Figure 2).

Demographic Variable	Category	Estimated Percentage Who Had a Living Wi	
	Calegory	Who had a Living W	
Age	18 - 34	11%	
_	35 – 49	22%	
	50 - 64	23%	
	65+	32%	
Race	Caucasian	23%	
	African-American	9%	
Gender	Male	19%	
	Female	21%	
Education	Less then high school	21%	
	High school graduate	12%	
	Some college	16%	
	College graduate	25%	
Marital Status	Married	17%	
	Not married	21%	
Religion	Evangelical Protestant	15%	
	Traditional Protestant	19%	
	Catholic	22%	
	Non-Christian/Not religious	27%	

The findings of this study are fairly consistent with the general body of research concerning advance directives, which suggest that persons with higher levels of education and higher socioeconomic status are more likely to have completed an advance directive than are other individuals. African-Americans, individuals who have lower levels of education, the underinsured, and the cognitively-impaired are believed to be the least likely to have living wills. Prior research has also suggested that an individual who has previously witnessed negative consequences associated with a friend or family member not having an advance directive may be more inclined to execute one for themselves, in order to avoid similar consequences in the future.

Another Virginia-based study focused on the utilization of advance directives by Medicare beneficiaries admitted to Virginia hospitals. This study, conducted by the Virginia Health Quality Center (VHQC), used data from 22 hospitals which volunteered to participate. The study found that:

- 63 percent of patients' medical records contained documentation indicating that information concerning advance directives had been provided to patients;
- 2) of those records, 42 percent did not contain documentation that the information provided by the hospital had been acknowledged with the signature of the patient or her designee; and
- 3) 37 percent of the patients who had been informed about advance directives actually had an advance directive in their medical records.

After VHQC informed the hospitals of the results, the nine hospitals with the lowest rates of compliance agreed to participate in a quality improvement effort intended to bring themselves into closer compliance with the PSDA. Following a six-month intervention period, the percentage of Medicare beneficiaries whose medical records contained an advance directive increased from 27 percent to 47 percent.

Joint Commission on Health Care Survey of Virginia Nursing Facilities and Hospitals Indicates That In a Majority of Facilities No More Than 40 Percent of Individuals Have An Advance Directive

A JCHC staff survey asked hospitals and nursing facilities to provide their best estimate of the percentage of their patients or residents who have some type of an advance directive. This could include a living will, health care power of attorney, or both. Survey respondents were asked to provide an estimate within a series of given ranges. Sixty-three percent of all respondents estimated that no more than 40 percent of their patients or residents have an advance directive. Thirty-four percent of all facilities estimated that less than 20 percent of their patients or residents have an advance directive. Conversely, nine percent of all respondents estimated that more than 80 percent of their patients or residents have an advance directive. Figure 3 summarizes these survey data.

Figure 3 Estimated Percentage of Individuals in Virginia Hospitals and Nursing Facilities Who Have An Advance Directive							
Estimated Percentage of Individuals With An Advance Directive	Percentage of Total Respondents Reporting Estimates In This Range	Percentage of Nursing Facility Respondents Reporting Estimates In This Range	Percentage of Hospital Respondents Reporting Estimates In This Range				
Less than 20 %	34%	24%	55%				
21 – 40%	29%	24%	40%				
41 – 60%	15%	22%	0%				
61 – 80%	11%	16%	0%				
Greater than 80%	9%	14%	0%				
Unknown	2%	0%	5%				

Note: 128 survey responses were received. Survey response rate was 37 percent. Source: Joint Commission on Health Care staff survey analysis.

Nursing facilities reported greater utilization of advance directives among their residents than hospitals did among their patients. For example, 55 percent of hospitals responding to the survey estimated that less than 20 percent of their patients had advance directives. Only 24 percent of nursing facilities responding to the survey, by contrast, estimated that less than 20 percent of their residents had advance directives. Since the total response rate to the survey was only 37 percent, any conclusions to be drawn from the survey results must be limited simply to the respondents and not generalized to all nursing facilities and hospitals in Virginia. Among the respondents, however, there are some possible factors that may be useful in interpreting the results:

- some facilities likely serve a population drawn more heavily from those socioeconomic groups who are thought to be more resistant to executing an advance directive; or
- some facilities may be providing information and assistance concerning advance directives more effectively than others.

A Lack of Awareness Concerning Advance Directives Among the General Public Is Typically Cited As A Major Potential Barrier to Greater Utilization

There appears to be a general consensus among health care providers, advocates for the elderly, and the legal profession that the general public does not have a sufficient level of awareness and understanding concerning advance directives. This relative lack of widespread public understanding stands as a formidable barrier to greater utilization of advance directives. Based on interviews and literature reviews conducted by JCHC staff, common public misperceptions about advance directives appear to include the following:

- an attorney is needed in order to execute the document;
- they are only designed for and used by old, sick, or dying people;
- they will result in total medical abandonment and no palliative care measures will be taken;
- withdrawing treatments such as artificial hydration will result in greater discomfort;
- they are not designed in the patient's best interest but rather are designed by health care providers to reduce costs;
- the physician will initiate a discussion about the patient's wishes, and only if it is deemed necessary in the near future;
- the patient's family will agree on treatment decisions and can do everything an advance directive does, so a formal document is not necessary; and
- discontinuing or refusing life support constitutes suicide.

In all likelihood, basic human nature is probably the greatest single obstacle to greater utilization of advance directives. Several physicians and attorneys interviewed by JCHC staff stated their opinion that most people are not comfortable focusing on the fact that they will one day die, and acknowledging that at some point they will have to make a variety of plans in recognition of that fact.

A Lack of Sufficient Awareness of Advance Directives Among Health Care Practitioners Has Been Cited As Another Potential Barrier To Increased Utilization

Some physicians interviewed by JCHC staff described a variety of circumstances and situations within the medical profession as posing potential barriers to greater use of advance directives among the general public. As described by individuals interviewed and surveyed by JCHC staff, these barriers include a lack of sufficient incentives and time to discuss advance directives, and insufficient knowledge of advance directives. Two physicians stated as follows:

There are no rewards for a physician to bring up advance directives, other than to do the right thing. To do so means you have failed to cure their cancer, and that you have no treatment left. In other words, I am not smart enough to figure out how to make you better.

* * *

Within the medical profession, there is confusion and tremendous ignorance about advance directives. Physicians do a poor job asking their patients about advance directives. However, the medical profession is making an effort to improve.

One hospital executive stated the following:

I am not convinced that many physicians are unaware of the existence of health care directives. More often, physicians do not see them as helpful, are uncomfortable with addressing the issue with their patients, or do not know an appropriate method to help a patient complete one. Helping a patient complete an advance directive also requires time that practices are unwilling or unable to spend in an environment focused more on "productivity". This is not a criticism, just a fact. Patients also enter care with physicians at a time when the need for an advance directive is not obvious, and then is never revisited when the patient enters the terminal stage of an illness. Raising the issue when it is not an obvious need makes patients uncomfortable.

There are Some Situations Which Could Arise Within A Health Care Setting That Could Pose Potential Obstacles to The Enforcement of Provisions of an Advance Directive

End-of-life situations can be extremely emotional and even traumatic experiences for everyone involved. Within such an environment, decision making concerning a patient's medical care and treatment can be quite challenging. Based on interviews, surveys, and literature reviews conducted by JCHC staff, it appears that several types of scenarios could arise within a health care setting which could contribute, alone or in concert with other factors, to a chain of events in which the provisions of an advance directive are not honored. This does not mean that a lack of enforcement of advance directives is frequent or commonplace, only that it could happen.

Specific types of potential scenarios under which an advance directive might not be honored include:

- family opposition to a patient's wishes that no life-prolonging measures be taken;
- physician concerns about litigation on the part of the patient's family members who want life-prolonging measure to be taken;
- vagueness and lack of specificity in provisions of advance directives, which can make interpretation of a patients wishes difficult, particularly if there is no agent designated by a health care power of attorney;
- physician is unfamiliar with the patient, and has not had any prior discussion about the patient's preferences;
- patient changes treatment preferences constantly, or has questionable competency;
- difficulty making a medical determination concerning when and if further treatment for a terminally ill individual becomes futile;
- failure of the individual to deliver the advance directive to the appropriate entities such as their health care power of attorney, physicians and health care facilities; and

 failure to place advance directive in the patient's medical chart, particularly in a situation where a patient filled out an advance directive in one health care facility and is subsequently transferred to another health care facility, and the advance directive fails to accompany the patient to the new facility.

Some individuals have described an additional potential obstacle to enforcement of the provisions of an advance directive. A situation could arise in which an individual states in his advance directive that he <u>does</u> wish to receive life-prolonging procedures, and could also list certain types of specific treatments that he wishes to receive. However, §54.1-2990 of the *Code of Virginia* states that "nothing in this article shall be construed to require a physician to prescribe or render medical treatment to a patient that the physician determines to be medically or ethically inappropriate." This section of the HCDA does provide, however, that if the physician's determination is contrary to the terms of an advance directive, or contrary to the treatment decision of another person designated by statute to make a health care decision, the "physician." The *Code of Virginia* is silent concerning possible implications for patients and physicians in situations in which a replacement physician can not be obtained.

There Appears to Be Some Disagreement Concerning The Extent To Which Advance Directive Provisions Are Enforced

The American Medical Association's (AMA) Code of Medical Ethics states that "The social commitment of the physician is to sustain life and to relieve suffering. When the performance of one duty conflicts with the other, the preferences of the patient should prevail." The AMA Code of Medical Ethics states further that "The principle of patient autonomy requires that physicians respect the decision to forego life-sustaining treatment of a patient who possesses decision-making capacity." The AMA's Policy Compendium describes advance directives as "the best insurance for individuals that their interests will be promoted in the event they become incompetent."

During the course of its study, JCHC staff interviewed a wide range of professionals from the medical, legal, and health care provider arenas. Most of the individuals who were interviewed did not indicate that a lack of enforcement of advance directives was a significant problem. For example:

We may know individual physicians who are not keen on advance directives, but at the facility level, the hospital level, advance directives are honored.

* * *

I think physicians are okay with the idea of advance directives. It is the general public that needs to be educated.

* * *

Once an advance directive is drawn up, enforcement is not much of an issue except in rare cases.

Two individuals, neither of whom were physicians, interviewed by JCHC staff did express concern with the extent to which the provisions of advance directives are honored.

I have seen, on more occasions than I am comfortable with, where advance directives were ignored.

* * *

We know that physicians are not honoring advance directives.

The JCHC survey of Virginia hospitals and nursing facilities also indicated that there is concern, among representatives of some facilities, about the extent to which the provisions of advance directives are honored. A majority, 60 percent, of survey respondents, did not perceive any problem with the enforcement of advance directives in Virginia. On the other hand, 28 percent of respondents agreed with the statement that "The provisions of advance directives are often not followed by physicians do to various legal or ethical concerns." Twelve percent of survey respondents did not express any opinion on this issue. JCHC staff did not learn of any actual instances of advance directives not being honored in Virginia.

IV.

Methods To Increase and Improve Utilization and Acceptance of Advance Directives

The American Medical Association (AMA) Has Issued Recommendations to Improve Utilization of Advance Directives

According to the AMA, "more rigorous efforts in advance care planning are required in order to tailor end-of-life care to the preferences of patients so that they can experience a satisfactory last chapter in their lives." The AMA's Council on Ethical and Judicial Affairs recently recommended five strategies, as part of its Code of Medical Ethics, which it believes have the capability to enhance end-of-life decision-making:

- Advisory documents which relay the wishes of the patient and statutory documents which grant physicians immunity from malpractice as a result of following patients' wishes should be combined into one document.
- Advisory documents should be based on validated worksheets, thus ensuring reasonable confidence that preferences for end-of-life treatment can be fairly elicited and recorded, and that they are applicable to medical decisions.
- Physicians should discuss preferences for end-of-life treatment with either their patients or the designated proxies ahead of time and document those preferences appropriately.
- Central repositories should be made available so that documents that guide physicians during end-of-life situations, as well as those that list patients' personal information, may be easily accessible.
- A variety of orders should be permitted for use, which appear on the doctor's order sheet. This sheet informs physicians of the wishes that individual patients or their families have regarding treatment measures that may or may not be taken. This would assist health care facilities in following patients' wishes regarding treatment. For example, physicians could be allowed to use Full Comfort Care Only (FCCO); Do Not Intubate (DNI); Do Not Defibrillate (DND); Do Not Leave Home (DNLH); Do Not Transfer (DNTransfer); No Intravenous Lines (NIL); No Blood Draws (NBD); No Tube Feeding (NTF), and No Vital Signs (NVS) orders. These orders would allow for individuals with very specific treatment wishes to express those

wishes concisely, and thus avoid unwanted treatment that might arise from vague forms.

The AMA Has Developed An Educational Curriculum For Physicians Concerning End of Life Care

The AMA's Education for Physicians on End of Life Care (EPEC) project is designed to educate all U.S. physicians on the essential clinical competencies required to provide quality end-of-life care. One of the primary components of EPEC is a standardized, core curriculum that provides physicians with the basic knowledge and skills needed to appropriately care for dying patients. EPEC teaches fundamental skills in communication, ethical decisionmaking, palliative care, psychosocial considerations, and pain and symptom management. One of the EPEC modules covers advance care planning. This module:

- defines advance care planning and defines its importance,
- describes the steps of the advance care planning process,
- describes the role of patient, proxy, physician, and others,
- distinguishes between statutory and advisory documents,
- identifies pitfalls and limitations in advance care planning, and
- describes how to utilize planning to help put the patient's affairs in order.

In the first half of 1999, the curriculum was presented to a select group of 250 physician-educators through a series of regional conferences. Eight physicians from Virginia attended one of these conferences. According to the AMA, a copy of the EPEC curriculum will be provided to all physicians who are AMA members; presidents of national, state, and county specialty medical societies; medical school deans; and major medical organizations. The AMA anticipates that recipients of the curriculum will use it, in whole or in part, as a basis for establishing educational programs in their group practices, organizations, schools, and institutions.

The Virginia Board of Medicine Has Drafted Proposed Regulations Establishing Continued Competency Requirements of Physicians

Section 54.1-2912.1 of the *Code of Virginia* requires the Board of Medicine (BOM) to prescribe by regulation such requirements as may be necessary to ensure continued practitioner competence. In promulgating the regulations, the statute requires the BOM to consider (1) the need to promote ethical practice, (2) an appropriate standard of care, (3) patient safety, (4) application of new medical technology, (5) appropriate

communication with patients, and (6) knowledge of the changing health care system.

In response to this statutory requirement, the BOM has drafted proposed regulations that require at least 60 hours of continuing learning activities on the part of physicians every two years as a condition of renewing an active medical license. The draft regulations are designed to encourage and foster self-directed practitioner participation in education. Thirty of the required 60 hours must be documented by an accredited sponsor or organization sanctioned by the profession to designated learning activities. The other 30 hours may be self-documented by physicians. If the proposed regulations are given final approval by the BOM, they will become effective on January 1, 2000. However, pursuant to the regulations, license renewal would not be affected by the new requirements until 2002. Physicians could be encouraged to learn more about end-of-life care issues, including advance care planning and advance directives, in the course of fulfilling their continuing medical education requirement.

The AMA Council on Ethical and Judicial Affairs Has Recommended A Process-Based Approach For Making Treatment Futility Determinations.

As was previously discussed, one of the potential obstacles to the enforcement of provisions of an advance directive involves difficulty in making a medical determination concerning if and when treatment for a terminally ill individual becomes futile. The Council on Ethical and Judicial Affairs reports that it "finds great difficulty in assigning a definition to the term futility since it is inherently a value-laden determination." Thus, the Council favors a fair process approach for determining, and subsequently withholding or withdrawing, what is believed to be futile care. The report of the Council on Ethical and Judicial Affairs states that the recommended process insists on "full and fair deference to the patient's wishes, placing limits on this patient-centered approach only when the harm to the patient is so unseemly that, even after reasonable attempts to find another institution, a willing provider of the service was not found." Elements of the recommended process include the following:

1. Earnest attempts should be made to negotiate a prior understanding between patient, proxy, and physician about what constitutes futile care for the patient and what falls within acceptable limits for the physician, family, and possibly also the institution. This is best done before critical illness occurs. If serious disagreement is unresolvable, provisions can be made for a sensitive and orderly transfer of care at that time in order to preempt later conflicts.

- 2. Joint decisionmaking should also be made at the bedside between patient or proxy and physician, making use of outcomes data whenever possible, and abiding by established standards of deliberation and informed consent.
- 3. The assistance of an individual consultant and/or a patient representative is a further step that is often helpful to reach resolution within all parties' acceptable limits.
- 4. An institutional committee such as an ethics committee may be involved if disagreements are irresolvable. Such a committee should be structured to provide for full voice for the patient or proxy perspective.
- 5. If the outcome of the institutional process coincides with the patient's wishes but the physician remains unpersuaded, arrangement may be made to transfer the patient to another physician within the institution. Alternatively, if the outcome coincides with the patient's wishes, transfer to another institution may be sought.
- 6. Finally, if transfer is not possible because no physician and no institution can be found to follow the patient and/or proxy's wishes, it may be because the request is "offensive to medical ethics and professional standards in the eyes of a majority of the health care profession." In such a case, by ethics standards, "the intervention in question need not be provided, although the legal ramifications of this course of action are uncertain."

Health Care Facilities in Virginia Appear to Be Making Solid Efforts to Comply With the PSDA, But Limitations of PSDA's Effectiveness Are Recognized

Based on the results of the JCHC staff survey, it appears that hospitals and nursing facilities in Virginia are making substantial efforts to comply with the provisions of the PSDA. In particular, the distribution of information concerning advance directives, and subsequent follow-up with patients and residents, appears to be well-integrated into the facilities' admission processes. Furthermore, 99 percent of the JCHC survey respondents reported that they will assist their patients or residents in executing an advance directive, if one has not already been executed. That type of activity goes beyond what the PSDA actually requires, and is commendable. However, several survey respondents, as well as other individuals interviewed by JCHC staff, question the appropriateness and effectiveness of discussing and executing advance directives in an institutional setting such as a hospital or a nursing home, and particularly as part of an admissions process. According to this view, admission to a hospital or a nursing home often occurs during crisis-like situations. Given the importance of advance planning discussions as they pertain to end-of-life care decisions, several individuals reported to JCHC staff that advance directives, and advance care planning, are best dealt with and discussed in a non-crisis, non-institutional setting, such as a primary care physician's office. Representatives of two health care institutions stated as follows:

The problem is that by the time someone is admitted to the facility, more often than not, he or she is not of sound mind due to decline in cognitive ability and therefore is not able to execute an advance directive.

* * *

I have repeatedly stated that the hospital is not the place to initiate filling out the forms. That needs to be done in the physician's office or another setting. It is often too late or not appropriate to address advance directives when they are acutely ill.

Many physicians, in all likelihood, do discuss advance directives with their patients. However, physicians and physician's offices are not covered by the PSDA, and therefore are not required to comply with its informational and educational provisions. Some individuals interviewed and surveyed by JCHC staff indicated that primary care physicians ought to be more involved in educating their patients about advance directives. However, a sufficient level of awareness of advance directives among physicians was cited by some physicians as a potential obstacle.

There is vast confusion on the part of everyone, including the general public, physicians, nurses, and emergency medical technicians. A particular source of confusion involves the difference between advance directives and do-not-resuscitate orders. Some physicians encourage their patients not to execute advance directives, due to concerns that other medical staff will interpret the advance directive so as to provide no treatment to the individual.

* * *

Probably about 50 percent of primary care physicians really talk to their patients about advance directives. However, within the past five years medical schools have begun to pay more attention to end-of-life care issues. I think the new generation of physicians will pay more attention to advance directives.

* * *

Physicians are familiar with the concept of advance directives. However, they may not be as familiar with the mechanics of actually executing an advance directive.

One attorney interviewed by JCHC suggested that voluntary efforts could be made to encourage physicians to include a question about advance directives on paperwork that is completed by their new patients (i.e. in addition to asking about a patient's insurance coverage, also ask whether he or she has a written advance directive). In 1991, the Virginia Hospital Association's Task Force on Patient Self-Determination identified, as an educational strategy, encouraging health care practitioners in private practice to provide information about advance directives in their waiting rooms.

One hospital executive suggested developing a "frequently-asked questions" document for physicians which is quick to read and addresses how the advance directive can be beneficial to them in their interaction with patients. The executive stated that the document should be mailed to every practicing physician in the state perhaps two or three times a year. According to this individual, the document should address:

- how the HCDA provides legal support when an advance directive is in place;
- methods to gain support when necessary from the hospital (e.g. ethics committee consultations) in conflict situations with families;
- how an advance directive helps create a framework and expectations regarding care choices that can be supportive when conflicts arise, and why taking the time now to help a patient do an advance directive may help solve or avoid complicated situations later.

One physician suggested that the Virginia Board of Medicine or the Medical Society of Virginia could serve as a means of distributing information concerning advance directives to physicians. It was also suggested that hospitals be encouraged to include information about the benefits of advance directive planning in their orientation programs for new physicians. This educational segment should also describe the internal processes the hospital has for dealing with conflicts around health care decisions.

Given the proper training on advance directives, nurses, medical technicians, home health workers, and physicians' assistants could also be given greater responsibility for ensuring that advance care planning occurs. Nurses, especially, should be directed with initiating advance care planning since they often act in an educational manner with patients. Nurses already possess both the knowledge and skill for discussing intimate issues with patients, and they could serve as a valuable asset for ensuring patient self-determination.

Social workers, chaplains, lawyers, religious leaders, and other community leaders might also serve as a gateway to patients in need of advance directive awareness. In rural areas, where health providers are more scarce, educating individuals such as religious leaders about advance directives would ensure that there are individuals in all sorts of communities to promote advance care planning. Combining community leaders with medical professionals to provide consumer information about advance care planning will further ensure that all the individual's questions – medical, spiritual, and personal - concerning advance care planning are addressed.

There Appears to Be Support for Efforts to Increase Utilization of Advance Directives in Virginia

Following the enactment of the PSDA in 1990, there were numerous education and outreach initiatives within Virginia concerning advance directives. These were conducted by the Virginia Hospital and Healthcare Association, the Virginia Department for the Aging, Area Agencies on Aging, the Virginia State Bar, as well as several other entities. Currently, health care facilities continue to implement activities designed to comply with the informational and educational requirements of the PSDA. Nevertheless, there does appear to be a sense among health care providers that still more needs to be done to promote awareness and understanding of advance directives. For example, 85 percent of the hospitals and nursing facilities responding to JCHC survey believe that the State of Virginia should do more, through education and outreach activities, to promote increased utilization of advance directives. Representatives stated as follows: More assistance could be used in educating the public regarding the difference between a medical power of attorney and an advance directive <u>and</u> at what point they become applicable to care provisions.

* * *

Unless someone is hospitalized or unless their physician's office has educational information in their lobby, there is very little education done with the general public. We need to inform people how important this information is and how they should see to it that their wishes are known. They need to know what an advance directive is, where it needs to be, and who needs to know of its existence.

There does not appear to be any shortage of informational material concerning advance directives. A significant amount of documentation is available, for example, via the Internet. However, it is possible that adequate distribution of sufficient information to the individuals who need it, and at the appropriate time, may be more of a challenge. As one nursing facility representative stated:

Those of us who work in health care know about advance directives and are exposed to situations that can help us make informed choices, but many in the public are not.

One physician interviewed by JCHC staff stated that the role of educating the public concerning advance directives has been largely left to the private sector, but he believes that there is an educational role for the state to play on this issue:

I do not believe that there is equal opportunity for education within the private sector. How many people have attorneys? How many people have wills? How many people are regularly involved with the health care system?

One Area Agency on Aging representative stated that a number of activities have been undertaken in the AAA's service area to educate and inform the public about advance directives. However, the AAA has not been able to do as much in this area as it would like to due to a lack of resources, and competing demands on its staff. Several advocates for the elderly have expressed the opinion that efforts to promote greater awareness and utilization of advance directives should be made within the framework of a coordinated state elder rights program. During the 1999 General Assembly Session, a budget amendment was introduced that would have required the Virginia Department for the Aging to contract with one entity for the administration of all elder rights programs. However, that amendment was not approved.

As previously discussed, many public misperceptions surround advance directives. This will continue to serve as a major barrier to utilization of advance directives unless successful educational efforts can counter them. At this point in time, a cooperative, coordinated effort with some level of state support could be helpful. Ideally, efforts could be made in both health care and non-health care related settings. For example, primary care physicians, local ombudsman, and area agencies on aging could all play valuable roles in such an effort. A cooperative, coordinated effort should draw upon existing resources, such as the <u>Your Right To</u> <u>Decide</u> information pamphlet prepared by the VHHA. While VHHA charges a nominal fee for the printed pamphlet, the text itself is noncopyrighted, is available for free, and could serve as a basis for a more widespread education and outreach effort.

A particularly notable endeavor to increase advance directive utilization was undertaken by major health systems in La Crosse, Wisconsin in 1991. The "collaborative, systematic, community-wide" program was called *Respecting Your Choices* and included:

- locally developed patient education materials;
- availability of the materials throughout the community;
- uniform training and continuing education of more than 120 local advance directive, non-physician educators;
- access to advance directive educators at all health care organizations;
- common policies and practices of maintaining and using advance directive documents; and
- documentation of advance directive education in the patient's medical record when such documentation occurred in a health care organization.

A telephone survey conducted in the area prior to the program found that 15 percent of the population had some form of written advance directive. Two years after the program began, researchers found that utilization increased to 85 percent of the population. Furthermore, 95 percent of those documents were found in patients' medical records.

Some Respondents to the JCHC Survey Report That Some Type of An Advance Directive Registry Would Be Beneficial

As was previously mentioned, the American Medical Association has recommended that central repositories be established for advance directives. A few respondents to the JCHC survey expressed support for this type of repository or registry concept. For example:

It is probably a far-fetched idea but it would be great if there were a storehouse somewhere in the state that patients could send a copy of their advance directives to. These could be scanned and then •accessed by every provider of services via the Internet and a copy printed off as needed.

* * *

A computerized list to which all states subscribed would give immediate access to information about advance directives for any individual, assuming the individual signed up.

In the absence of a computerized registry several respondents to the JCHC survey reported that a short, simple, wallet-sized form or card that an individual could carry on his or her person could still be beneficial.

Only one state, California, has established a registry for advance directives. The registry is purely voluntary and is administered by the California Department of Justice. However, according to a representative of the California Legislature's Aging and Long-Term Care Commission, the registry is poorly utilized by individuals, and has not been successful. JCHC staff were told that citizen concerns regarding confidentiality of the registry data may be a primary factor underlying the registry's low utilization. Ohio has made a prior unsuccessful attempt to implement a registry for advance directives.

The U.S. Living Will Registry is privately-administered service that maintains copies of individuals' advance directives. The registry is available free of charge to individuals and hospitals nationwide. In order to participate, individuals must submit a copy of their living will. The registry scans the living will into a computer, and maintains a hard copy. Participating hospitals can call a toll-free, 24 hour telephone number to determine whether an individual has a living will, and to request that a copy be faxed to them. While the registry is currently very small, with only 1,000 advance directives on file and 130 participating hospitals, the registry is considering plans for future expansion. Four Virginia hospitals participate in the U.S. Living Will Registry: Piedmont Geriatric (Burkeville), Shenandoah Memorial (Woodstock), Norton Community Hospital (Norton), and Halifax Regional Hospital (South Boston). One potential element of constructing an advance directive registry could include allowing an individual to place an indicator on his or her driver's license signifying that an advance directive has been executed, similar to the organ donor indicators that are commonplace across the United States. Eight states - Alaska, Illinois, Minnesota, Missouri, Ohio, South Dakota, and Texas - have statutory provisions that allow their residents to place some type of indicator on their drivers licenses to signify that they have executed an advance directive. Naturally, the provisions of the different state statutes vary. In Ohio, applicants for a driver's license and state identification card are asked if they have executed a valid power of attorney for health care, a declaration governing the use of lifesustaining equipment and if they wish the driver license or identification card to indicate that the power of attorney and life-sustaining equipment instruments have been executed.

The primary benefit to be derived from such a policy would be to provide another potential means by which a health care practitioner could be made aware of the fact that the individual has executed an advance directive. However, an indicator on a driver's license would not indicate where the advance directive is located or what its provisions are, both of which are essential elements. The Virginia Department of Motor Vehicles (DMV) has expressed strong reservations to JCHC staff about adding an advance directive indicator to a driver's license. DMV cited additional burdens that would be placed on license applicants and DMV personnel by such a requirement. DMV stated that such a requirement would require a statutory change, and would create a new requirement for individuals to notify DMV if they later change their living will designation. DMV also cited liability concerns should incorrect information accidentally be keyed.

The development of a state organ donor registry is currently being considered by the Virginia Transplant Council and the Joint Commission on Health Care, but it is not yet clear if or when such a registry will be actually be implemented. If a Virginia organ donor registry is implemented, it could potentially be expanded or modified in the future to include data concerning advance directives. It appears fairly appropriate and defensible in concept to include organ donors and advance directives in a single registry, particularly since Virginia's suggested advance directive form allows an individual to make an anatomical gift. Nevertheless, it would probably be most beneficial at this point in time to allow ongoing efforts to establish an organ donor registry to proceed without being encumbered by other requirements, such as advance directives. However, the inclusion of advance directives in a state registry, particularly one the utilizes the existing infrastructure of a statewide organ donor registry, should be considered at a later date.

The Suggested Format of Virginia's Advance Directive is Fairly Generic, But It is Not Mandatory and Other Types of Advance Directive Forms May Be Used

The suggested advance directive form contained in the *Code of Virginia* is a relatively generic form, and represents a balance between specificity of provisions and length of the document. Whether the form should remain fairly generic or become more detailed is a valid public policy question. Checklist-type forms, in which individuals may check off which treatments they do or do not desire (i.e. intubation, artificial hydration and feeding, cardiopulmonary resuscitation, defibrillation, and mechanical ventilation), may help eliminate some uncertainty that surrounds vague provisions. Using a more detailed but longer form, a physician may be less likely to be placed in the position of serving as the interpreter for a patient's values, and may be much more comfortable to withhold specified treatments. However, overly specific forms may unduly restrict physicians with little assurance to the physician whether the patient's decisions took into account the situation at hand.

Virginia's suggested format is not mandatory. Indeed, there are several different types of forms in use. For example, some nursing facilities have their own unique advance directives whose language and provisions vary from those given in the *Code of Virginia*. Some of these forms utilize a check-off format in which residents may specify certain types of treatment that they do or do not want. Other forms are less comprehensive than the suggested state form in that they do not provide the means for making an anatomical gift. Others appear to have become somewhat out of date in that they reference the Virginia Natural Death Act of 1983, as opposed to the Virginia Health Care Decisions Act of 1992.

Virginia's suggested advance directive form has several positive attributes, particularly that it combines the living will, health care power of attorney, and an anatomical gift designation into a single form. The form has also been described as achieving a delicate, but essential, balance between patient autonomy and physician beneficence. A few criticisms have been directed at the suggested state form. These include that the suggested form is:

- too generic and vague,
- focused on specific treatment modalities as opposed to value-based outcomes, and
- biased towards withholding or withdrawing treatment as opposed to providing treatment.

Nevertheless, the suggested state form appears to be widely used and available throughout Virginia. For example, the Virginia Hospital and Healthcare Association makes the suggested form available to all of its members. The Medical Society of Virginia makes a similar advance directive form available to its members, but this form does not contain a separate section for the appointment of an agent to make an anatomical gift. The widespread use of general forms supports the theory that the formal advance directive document should serve primarily as a tool for initiating advance care planning discussions.

Some Concerns Have Been Expressed About Portability of Advance Directives Among Different Health Care Facilities in Virginia and Other States

Section 54.1-2993 of the *Code of Virginia* clearly states that Virginia will honor advance directives executed in compliance with the laws of other states. In other words, an advance directive executed in North Carolina shall be honored by health care providers located in Virginia. However, the extent to which an advance directive executed in Virginia, in compliance with the HCDA, will be honored by a health care provider in a neighboring state is somewhat unclear. One attorney from Southern Virginia said his clients had experienced problems with North Carolina facilities, so his law firm changed the advance directive form they prepare for their clients in order to comply with the provisions of North Carolina. However, another attorney, who represents health care facilities in Southern Virginia, said that he has not experienced such problems.

There are variations between Virginia's health care decisions act and similar statutes in neighboring states. These include whether or not an advance directive must be notarized, who can be designated to serve as an agent via a health care power of attorney, and who may witness the signature of an advance directive (Figure 4). As a rule, Virginia's provisions are less restrictive than many of its surrounding states. It is possible that these differences could be serving as potential obstacles to honoring an advance directive for those Virginians who are referred to outof-state providers for medical treatment. This could occur, for example, if a facility in North Carolina refused to honor an advance directive executed in Virginia because it had not been notarized.

Some respondents to the JCHC survey stated that portability of advance directives among health care facilities does not appear to be a great problem in Virginia. A few other respondents, however, stated that portability can be a problem, particularly when an individual is transferred from one health care facility to another.

Figure 4 Comparison of Selected Provisions of Virginia's Health Care Decisions Ac With Statutory Provisions of Neighboring States			
District of Columbia	Provider of residential long term care facility	2 witnesses Special institutional requirements	Facility, Relative Heir Creditor Person responsible for care costs
Kentucky	Facility	2 witnesses or notarized	Relative Provider Facility Heir Person responsible for care costs
Maryland	Facility	2 witnesses Also recognizes oral directive to a physician with one witness	Agent At least one must have no financial interest in person's death
North Carolina	Provider	2 witnesses and notarized	Relative Heir Provider Facility Creditor
Tennessee	Provider	2 witnesses and notarized	Agent
Virginia	None specified	2 witnesses	Spouse Relative
West Virginia	Provider Facility	2 witnesses and notarized	Agent Attending physician Principal's signator Relative Heir Person responsible for costs

When a resident of this facility is sent to the hospital or a hospital emergency room, the advance directive is sent with them. The difficulty is that more often than not each institution seems to negate the directive if the directive is not on the particular institution's form.

* * *

It is very definitely the case that advance directives do not always follow individuals from one health care setting to another.

* * *

When a home health patient is discharged from the hospital, the home health agency doesn't get any medical documentation unless it asks for it. You are lucky to get a discharge summary. It would be nice to include an advance directive in the discharge summary.

The original do-not-resuscitate order is sent to the hospital, and then the nursing facility is unable to subsequently get the original form back [when the patient is discharged from the hospital].

* * *

To a large extent, these comments involve medical record keeping issues and practices within various facilities. Some survey respondents suggested that discharge interventions referencing advance directives can provide facility staff with a reminder to send along a patient's advance directive at the time of transfer to another facility. Nevertheless, 85 percent of the respondents to JCHC's survey of hospitals and nursing facilities expressed agreement that physicians are adequately informed about the existence of advance directives that have been executed by their patients. It appears that much of the concern expressed concerning portability between health care facilities may in fact be focused on do not resuscitate orders, as opposed to living wills or health care powers of attorney. The 1999 General Assembly amended the HCDA to create a durable do not resuscitate order to promote greater portability. However, a DDNR is not the same as an advance directive.

The Virginia Department of Health (VDH) is currently in the process of promulgating new regulations and forms to implement the use of durable do not resuscitate orders. Existing VDH regulations require that only an original DNR order, and not a copy, may be honored. According to a representative of the VDH Office of Emergency Medical Services (VDH/OEMS), this requirement is intended as a safeguard in the event that an individual has revoked a DNR order by destroying the original, but has not destroyed all of the copies of the form that might have been made. This regulatory requirement is somewhat different from the statutory provisions of the HCDA, which seems to implicitly authorize the use of a copy of an advance directive. Section 54.1-2983 requires a physician to make an advance directive, <u>or a copy of an advance directive</u>, a part of the declarant's medical records.

Some survey respondents and interviewees cited some concerns with DNR orders. These problems include difficulty obtaining the required forms from VDH/OEMS, patient dissatisfaction with the optional plastic wrist bracelet issued by VDH/OEMS, and the fact that only the original do-not-resuscitate form ,and not a copy, may be honored. VDH/OEMS annually distributes approximately 13,000 do not resuscitate forms, and 10,000 plastic wrist bracelets, in response to provider requests. VDH/OEMS is also considering expanding the choice of wrist bracelets that are issued for do not resuscitate orders. Currently, plastic bracelets are issued by VDH, but they have been frequently criticized as uncomfortable, unattractive, and stigmatizing.

The National Conference of State Legislatures Has Issued Recommendations Concerning The Use of Advance Medical Directives

The National Conference of State Legislatures and George Washington University's Center to Improve Care of the Dying (NCSL/GWU) have recommended approaches to improve deficiencies with the use of advance directives and to ensure that patients' treatment preferences are carried out. These recommendations, which were published in 1998 in <u>State Initiatives in End-of-Life Care: Policy Guide for</u> <u>State Legislators</u>, are as follows:

- 1) reduce inefficiency by combining various right to die statutes into one comprehensive act;
- 2) ensure flexibility to allow patients to modify their living wills to become more specific as conditions worsen;
- 3) emphasize the importance of patients' rights and understanding;
- 4) recognize other states' advance directives;
- 5) address do-not-resuscitate orders for emergency medical services; and

6) experiment with different strategies to make advance directives more accessible.

The substance of recommendations one, four, and five are clearly reflected within the provisions of the Virginia Health Care Decisions Act. The substance of recommendation two is at least partially reflected within the HCDA. Recommendations three and six, however, involve issues that are not strictly statutory or legislative in nature. Legislative bodies can play a role with enabling legislation, but implementation of these recommendations also requires cooperation and coordination of various public and private sector entities, both in and out of health care settings.

In discussing recommendation three, NCSL/GWU explains that advance directive forms should be part of a larger advance planning process, in which a patient's values and wishes are updated repeatedly over time. The report provides the following values questions as examples that may facilitate this process:

- What do you value most about your life?
- Do you think life should be preserved as long as possible? Why or why not?
- Can you think of any possible scenarios in which you might feel differently about the above question?
- Do your religious beliefs affect the way you feel about death?
- Should financial considerations be important when making decisions about medical care?
- Have you talked with friends and family about these issues?

NCSL/GWU note that "legislators could allow these types of questions to be appended to the state's form, thereby reducing the possibility that advance directives will substitute for discussion within families and between health care professionals and patients."

Florida's Commission on Aging with Dignity, with support from the Robert Wood Johnson Foundation, developed an advance directive document entitled *Five Wishes*. This is an eight-page document, with detailed instructions, designed to allow individuals to express their wishes for the following:

1) the person I want to make care decisions for me when I can't,

- 2) the kind of medical treatment I want and don't want,
- 3) how comfortable I want to be,
- 4) how I want people to treat me, and
- 5) what I want my loved ones to know.

According to the American Bar Association's Commission on Legal Problems of the Elderly, *Five Wishes* meets the legal requirements under the health care decision statutes of 33 states, including Virginia and most of its neighbors (District of Columbia, Maryland, North Carolina, and Tennessee). The form does appear to satisfy the provisions of the HCDA, in that it is a "voluntarily-executed, witnessed written document." However, the *Five Wishes* form does not elaborate on the wide variety of witnessing provisions among the states.

Legislation is Currently Pending in the United States Congress That Would Expand the Provisions of the 1990 Patient Self-Determination Act

Senate Bill 628 is referred to as the Advance Planning and Compassionate Care Act of 1999. This legislation would, if enacted into law, expand the scope and reach of the PSDA in several ways. The bill's provisions:

- require that each person's advance directive be placed in a prominent part of the medical record, so that they are readily available and visible to anyone involved in their health care;
- direct the Secretary of Health and Human Services to study matters relating to the creation of a national uniform policy on advance directives, including issues of: the election or refusal of lifesustaining treatment, palliative care and pain management, portability, immunity for health care providers for following the provisions of an advance directive, conditions where the directive takes effect, revocation of the document, criteria for terminal illness, and surrogate decision-making;
- require that every Medicare beneficiary have the opportunity to discuss health care decision-making issues with an appropriately trained professional;
- establish a clearinghouse and a 24-hour toll-free telephone hotline to provide consumer information about advance directives and end-oflife decisionmaking;
- establish portability of advance directives across state lines by providing that the statutory regulations of the state in which the

document was executed take precedence if the directive is presented in another state; and

• direct the Secretary of Health and Human Services to advise Congress on an approach to adopting the provisions of the Uniform Health Care Decisions Act for Medicare beneficiaries.

V. Policy Options

The following policy options are offered for consideration by the Joint Commission on Health Care regarding the utilization of advance directives in Virginia. However, these policy options do not represent the entire universe of options that the Joint Commission on Health Care may wish to pursue with regard to the use of advance directives. Furthermore, these policy options are not mutually exclusive. The Joint Commission on Health Care may choose to pursue two or more of these options.

Option I: Take no action.

- Option II: Introduce legislation to amend §54.1-2984 of the *Code of Virginia* in order to modify the suggested form of written advance directives by incorporating language designed to facilitate end-of-life discussions and decision making. New statutory language could be based on examples contained in <u>State Initiatives in End-of-Life Care: Policy Guide for State</u> <u>Legislators</u>. New statutory language could be added to the preamble of §54.1-2984 of the Code of Virginia, or as questions appended to the suggested form of written advance directives.
- Option III: Introduce legislation to amend §54.1-2984 of the *Code of Virginia* in order to modify the suggested form of written advance directives by incorporating language, as indicated in §54.1-2988 of the *Code of Virginia*, that a health care facility, physician, or other person acting under the direction of a physician shall not be subject to criminal prosecution or civil liability or be deemed to have engaged in unprofessional conduct, as the result of honoring the provisions of an advance directive or a durable do notresuscitate order.
- Option IV: Introduce a budget amendment directing the Virginia Department for the Aging to contract with the Virginia Association of Area Agencies on Aging to develop an educational and informational program designed to increase public knowledge of end-of-life care issues, and to increase public awareness and utilization of advance care planning and advance directives. (The dollar amount of this budget amendment will need to be determined).

Option V: Introduce a joint resolution requesting the Virginia Board of Medicine, the Medical Society of Virginia, the Virginia Academy of Family Physicians, the Virginia Hospital and Healthcare Association, the Virginia Health Care Association, the Virginia Association of Non-Profit Homes for the Aging, and other appropriate entities, to encourage their members to (1) include coverage of end-of-life care issues, advance care planning and advance directives in their continuing education programs; (2) promote discussion of end-of-life care issues and advance care planning in their treatment protocols; and (3) collaborate to develop mechanisms and procedures to foster effective and efficient transfer of advance directive documentation among health care practitioners and facilities.

APPENDIX A

.

.

. **у**

HOUSE JOINT RESOLUTION NO. 603

Directing the Joint Commission on Health Care to study the use of advance directives in the Commonwealth.

Agreed to by the House of Delegates, February 9, 1999 Agreed to by the Senate, February 18, 1999

WHEREAS, Americans' right of self determination includes the ability to make fundamental decisions regarding the quality of one's life; and

WHEREAS, this right has been reaffirmed in the Code of Ethics of the American College of Health Care Administrators; and

WHEREAS, when an individual becomes physically or mentally unable to make decisions regarding his or her medical treatment, that person's power of self-determination can be preserved through advance medical directives; and

WHEREAS, a living will and designation of another as having power of attorney help ensure that the wishes of the individual are known and carried out; and

WHEREAS, the federal Patient Self-Determination Act (PSDA), passed in 1989, requires that hospitals, nursing facilities, hospices, home health agencies, and health maintenance organizations that participate in Medicare and Medicaid provide all patients with written information about their rights under state law to accept or refuse medical or surgical treatment and to formulate advance directives; and

WHEREAS, interest in advance directives, or living wills, and advances in medical technology led to rapid enactment of state laws recognizing the patient's right to control treatment processes; and

WHEREAS, the number of states enacting such laws has grown from fourteen in 1983 to thirty-six in 1985, and forty-seven in 1996; and

WHEREAS, the legal planning tool most often used for health care decisions in Virginia is the advance medical directive or health care power of attorney which allows individuals to set guidelines for health care decisions and to appoint someone to act as their agent; and

WHEREAS, these tools can reduce the chances of conflict among family, friends, and health care providers during a time of medical need; and

WHEREAS, the use and enforcement of advance directives has varied among different demographic groups due to a number of factors, including: lack of knowledge of the existence of advance directives and lack of appreciation of the need for an advance directive; vagueness in the directive which would make it difficult to enforce; lack of knowledge by treatment professionals regarding the existence of a directive; lack of portability between health care professionals and locations including interstate reciprocity; debate over the ethical questions regarding the selective use of advance directives; and concern by health care professionals over honoring such directives; and

WHEREAS, increased attention has focused on a living will format which would include not only the medical wishes but also the personal, emotional, and spiritual wishes of seriously ill persons; and

WHEREAS, a document embodying this format, reviewed by the American Bar Association's Commission on Legal Problems of the Elderly, has been deemed legal in 33 states, including Virginia; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Joint Commission on Health Care be directed to study the use of advance directives in the Commonwealth. The study should include, but not be limited to: the percentage and categories of persons who utilized advance directives and methods to increase that number; the legal or ethical obstacles which inhibit the enforcement of the provisions of an advance directive; methods which would better inform health care practitioners about the existence of advance directives; and methods to insure portability and reciprocity for advance directives among health care providers and institutions as well as other states.

All agencies of the Commonwealth shall provide assistance to the Joint Commission, upon request. The Joint Commission shall complete its work in time to submit its findings and recommendations to the Governor and the 2000 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

APPENDIX B

.

•

.

.

SUGGESTED FORM OF WRITTEN ADVANCE DIRECTIVE SECTION 54.1-2984, CODE OF VIRGINIA

ADVANCE MEDICAL DIRECTIVE

I,, willfully and voluntarily make known my desire and do hereby declare:

If at any time my attending physician should determine that I have a terminal condition where the application of life-prolonging procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure

deemed necessary to provide me with comfort care or to alleviate pain (OPTION: I specifically direct that the following procedures or treatments be provided to me:

·····)

In the absence of my ability to give directions regarding the use of such life-prolonging procedures, it is my intention that this advance directive shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences of such refusal.

OPTION: APPOINTMENT OF AGENT (CROSS THROUGH IF YOU DO NOT WANT TO APPOINT AN AGENT TO MAKE HEALTH CARE DECISIONS FOR YOU.)

I hereby appoint (primary agent), of (address and telephone number), as my agent to make health care decisions on my behalf as authorized in this document. If (primary agent) is not reasonably available or is unable or unwilling to act as my agent, then I appoint ... (successor agent), of (address and telephone number), to serve in that capacity.

I hereby grant to my agent, named above, full power and authority to make health care decisions on my behalf as described below whenever I have been determined to be incapable of making an informed decision about providing, withholding or withdrawing medical treatment. The phrase "incapable of making an informed decision" means unable to understand the nature, extent and probable consequences of a proposed medical decision or unable to make a rational evaluation of the risks and benefits of a proposed medical decision as compared with the risks and benefits of alternatives to that decision, or unable to communicate such understanding in any way. My agent's authority hereunder is effective as long as I am incapable of making an informed decision.

The determination that I am incapable of making an informed decision shall be made by my attending physician and a second physician or licensed clinical psychologist after a personal examination of me and shall be certified in writing. Such certification shall be required before treatment is withheld or withdrawn, and before, or as soon as reasonably practicable after, treatment is provided, and every 180 days thereafter while the treatment continues.

In exercising the power to make health care decisions on my behalf, my agent shall follow my desires and preferences as stated in this document or as otherwise known to my agent. My agent shall be guided by my medical diagnosis and prognosis and any information provided by my physicians as to the intrusiveness, pain, risks, and side effects associated with treatment or nontreatment. My agent shall not authorize a course of treatment which he knows, or upon reasonable inquiry ought to know, is contrary to my religious beliefs or my basic values, whether expressed orally or in writing. If my agent cannot determine what treatment choice I would have made on my own behalf, then my agent shall make a choice for me based upon what he believes to be in my best interests.

OPTION: POWERS OF MY AGENT (CROSS THROUGH ANY LANGUAGE YOU DO NOT WANT AND ADD ANY LANGUAGE YOU DO WANT.)

The powers of my agent shall include the following:

A. To consent to or refuse or withdraw consent to any type of medical care, treatment, surgical procedure, diagnostic procedure, medication and the use of mechanical or other procedures that affect any bodily function, including, but not limited to, artificial respiration, artificially administered nutrition and hydration, and cardiopulmonary resuscitation. This authorization specifically includes the power to consent to the administration of dosages of pain-relieving medication in excess of recommended dosages in an amount sufficient to relieve pain, even if such medication carries the risk of addiction or inadvertently hastens my death;

B. To request, receive, and review any information, verbal or written, regarding my physical or mental health, including but not limited to, medical and hospital records, and to consent to the disclosure of this information;

C. To employ and discharge my health care providers;

D. To authorize my admission to or discharge (including transfer to another facility) from any hospital, hospice, nursing home, adult home or other medical care facility for services other than those for treatment of mental illness requiring admission procedures provided in Article 1 (§37.1-63 et seq.) of Chapter 2 of Title 37.1; and

E. To take any lawful actions that may be necessary to carry out these decisions, including the granting of releases of liability to medical providers.

Further, my agent shall not be liable for the costs of treatment pursuant to his authorization, based solely on that authorization.

OPTION: APPOINTMENT OF AN AGENT TO MAKE AN ANATOMICAL GIFT (CROSS THROUGH IF YOU DO NOT WANT TO APPOINT AN AGENT TO MAKE AN ANATOMICAL GIFT FOR YOU.)

Upon my death, I direct that an anatomical gift of all or any part of my body may be made pursuant to Article 2 (§32.1-289 et seq.) of Chapter 8 of Title 32.1 and in

accordance with my directions, if any. I hereby appoint as my agent, of (address and telephone number), to make any such anatomical gift following my death. I further direct that: ... (declarant's directions concerning anatomical gift).

This advance directive shall not terminate in the event of my disability.

By signing below, I indicate that I am emotionally and mentally competent to make this advance directive and that I understand the purpose and effect of this document.

(Date) (Signature of Declarant)

The declarant signed the foregoing advance directive in my presence. I am not the spouse or a blood relative of the declarant.

÷

(Witness) _____

.

`

APPENDIX C

SELECTED DEFINITIONS FROM VIRGINIA HEALTH CARE DECISIONS ACT SECTION 54.1-2982, CODE OF VIRGINIA

"Incapable of making an informed decision" means the inability of an adult patient, because of mental illness, mental retardation, or any other mental or physical disorder which precludes communication or impairs judgment and which has been diagnosed and certified in writing by his attending physician and a second physician or licensed clinical psychologist after personal examination of such patient, to make an informed decision about providing, withholding or withdrawing a specific medical treatment or course of treatment because he is unable to understand the nature, extent or probable consequences of the proposed medical decision, or to make a rational evaluation of the risks and benefits of alternatives to that decision. For purposes of this article, persons who are deaf, dysphasic or have other communication disorders, who are otherwise mentally competent and able to communicate by means other than speech, shall not be considered incapable of making an informed decision.

"Life-prolonging procedure" means any medical procedure, treatment or intervention which (i) utilizes mechanical or other artificial means to sustain, restore or supplant a spontaneous vital function, or is otherwise of such a nature as to afford a patient no reasonable expectation of recovery from a terminal condition and (ii) when applied to a patient in a terminal condition, would serve only to prolong the dying process. The term includes artificially administered hydration and nutrition. However, nothing in this act shall prohibit the administration of medication or the performance of any medical procedure deemed necessary to provide comfort care or to alleviate pain, including the administration of pain relieving medications in excess of recommended dosages in accordance with §§54.1-2971.01 and 54.1-3408.1. For purposes of §§54.1-2988, 54.1-2989, and 54.1-2991, the term also shall include cardiopulmonary resuscitation.

"Persistent vegetative state" means a condition caused by injury, disease or illness in which a patient has suffered a loss of consciousness, with no behavioral evidence of self-awareness or awareness of surroundings in a learned manner, other than reflex activity of muscles and nerves for low level conditioned response, and from which, to a reasonable degree of medical probability, there can be no recovery.

"Terminal condition" means a condition caused by injury, disease or illness from which, to a reasonable degree of medical probability a patient cannot recover and (i) the patient's death is imminent or (ii) the patient is in a persistent vegetative state.

· ·

. .

APPENDIX D

.

· · ·

·

·



JOINT COMMISSION ON HEALTH CARE

SUMMARY OF PUBLIC COMMENTS: ADVANCE DIRECTIVES STUDY (HJR 603)

Organizations Submitting Comments

A total of ten organizations submitted comments in response to the HJR 603 report on Advance Directives:

- AARP,
- Arlington Agency on Aging,
- Medical Society of Virginia,
- Northern Virginia Aging Network,
- Shenandoah Area Agency on Aging,
- Virginia Department for the Aging,
- Virginia Health Care Association,
- Virginia Health Quality Center,
- Virginia Hospital & Healthcare Association, and
- Virginia Poverty Law Center, Inc.

Policy Options Included in the HIR 603 Issue Brief

Option I Take No Action

Option II: Introduce legislation to amend §54.1-2984 of the Code of Virginia in order to modify the suggested form of written advance directives by incorporating language designed to facilitate end-of-life discussions and decision making. New statutory language could be based on examples contained in <u>State</u> <u>Initiatives in End-of-Life Care: Policy Guide</u> for State Legislators. New statutory language

1

could be added to the preamble of §54.1-2984 of the Code of Virginia, or as questions appended to the suggested form of written advance directives.

- Option III: Introduce legislation to amend §54.1-2984 of the Code of Virginia in order to modify the suggested form of written advance directives by incorporating language, as indicated in **§54.1-2988** of the Code of Virginia, that a health care facility, physician, or other person acting under the direction of a physician shall not be subject to criminal prosecution or civil liability or be deemed to have engaged in conduct, as the result of unprofessional honoring the provisions of an advance directive or a durable do not-resuscitate order.
- Option IV Introduce a budget amendment directing the Virginia Department for the Aging to contract with the Virginia Association of Area Agencies on Aging to develop an educational and informational program designed to increase public knowledge of end-of-life care issues, and to increase public awareness and utilization of advance care planning and advance directives. (The dollar amount of this budget amendment will need to be determined).
- Option V: Introduce a joint resolution requesting the Virginia Board of Medicine, the Medical Society of Virginia, the Virginia Academy of Family Physicians, the Virginia Hospital and Healthcare Association, the Virginia Health Care Association, the Virginia Association of Non-Profit Homes for the Aging, and other appropriate entities, to encourage their members to (1) include coverage of end-of-life

2

care issues, advance care planning and advance directives in their continuing education programs; (2) promote discussion of end-of-life care issues and advance care planning in their treatment protocols; and (3) collaborate to develop mechanisms and procedures to foster effective and efficient transfer of advance directive documentation among health care practitioners and facilities.

Overall Summary of Comments

The comments were generally favorable. Options IV and V received the greatest level of support, with eight commenters expressing support for Option IV, and seven expressing support for Option V. The remaining policy options received varying levels of support and opposition. Three of the commenters expressed support for Option II and four commenters expressed support for Option III. One commenter expressed support for Option I.

Summary of Individual Comments

AARP

William L. Lukhard, Vice Chairman, AARP State Legislative Committee, expressed support for Options II - V. According to Mr. Lukhard, the issue brief indicated some of the perceived and real obstacles to greater utilization of advance directives. Mr. Lukhard stated that "Education of individuals on advance directives is essential."

Arlington Agency on Aging

Terry Lynch, Director, expressed support for Options II – V. Ms. Lynch briefly described prior efforts of the Arlington Agency on Aging to educate and inform the public concerning advance directives. According to Ms. Lynch, "Only lack of funding has kept our agency from partnering with all the relevant provider agencies in the area and providing ongoing education about advance directives...."

Medical Society of Virginia (MSV)

Marni Langbert Eisner, Esq., Director of Legislative Affairs, stated in response to Option I that "there is no need for further action by the Virginia Legislature on this issue at this time because the medical profession is aggressively trying to be in the forefront to remedy any perceived problems in the use and implementation of advance directives." Ms. Eisner indicated that Options II and III were not necessary since current statutory provisions are sufficient. In response to Option IV, Ms. Eisner stated that it would "only target a small percentage of those who need to be educated about advance directives and other end-of-life issues." Ms. Eisner indicated that other population segments, in addition to the elderly, also need to be targeted for more education and outreach efforts. Ms. Eisner did indicate some support for Option V, by stating that the Medical Society of Virginia "would be eager to be involved in more outreach on this issue." Ms. Eisner stated further that the MSV is "willing to collaborate with the societies mentioned to revamp continuing education programs to include discussions on advance directives and end-of-life care, promote discussion of these issues in their treatment protocols, and develop mechanisms for better documentation between practitioners and families." According to Ms. Eisner, the MSV hopes that the Commission "will see Option V as a vote for continuing to improve the access to information on advance directives and end-of-life care."

Northern Virginia Aging Network (NVAN)

Erica F. Wood, Chair, Legislative Committee, expressed support for Options II – V. Ms. Wood commented that the Year 2000 NVAN state legislative platform includes "promotion of the concept of advance planning." Ms. Wood agreed with one of the issue brief's conclusions by stating that "promotion of advance planning should be within the framework of an overall Elder Rights program." Ms. Wood noted that, at a recent Elder Rights conference, participants "recognized that more advance planning would empower older Virginians and foster end of life care reflecting patients' wishes." Finally, Ms. Wood stated that area agencies on aging are well positioned to heighten public awareness of advance planning. According to Ms. Wood, "Funding the AAA network would leverage existing resources, since area agencies on aging already have in place a diverse set of regular outreach mechanisms."

Shenandoah Area Agency on Aging

Anna Elwood, RN, Ombudsman, expressed support for Options III – V. Concerning Option IV, Ms. Elwood stated that area agencies on aging can increase public knowledge and awareness of advance directives through "the local long term care ombudsman program, case management departments, at the senior centers, and at public forums conducted by the AAA." Ms. Elwood commented in regard to Option V that "It is essential that education regarding end-of-life care be incorporated into continuing education programs of all entities which are involved with long term care." Finally, Ms. Elwood describe the importance of the appropriate transfer of advance directives along the health care continuum, so that they follow the individual from one health care setting to another.

Virginia Department for the Aging (VDA)

William Peterson, Deputy Commissioner for Programs, stated that Policy Option IV "would conflict with the Department's new mandate in §2.1-373 of the <u>Code of Virginia</u> to act as a focal point among state agencies for education on aging issues."

Virginia Health Care Association (VHCA)

Mary Lynne Bailey, Vice President, Legal and Government Affairs, expressed support for Options IV and V. According to Ms. Bailey, based on the experience of VHCA members, "we see no need for statutory changes at this time." Ms. Bailey stated that "None of our members have indicated problems concerning advance directives to us."

Virginia Health Quality Center (VHQC)

Joy Hogman Rozman, Chief Executive Officer, expressed support for Policy Option IV. Ms. Rozman stated that "The VAAAA offers an existing, grassroots network of 25 local area agencies on aging and more than 20 years of experience in developing training and education activities for seniors."

Virginia Hospital & Healthcare Association

Susan Ward, Vice President, primarily expressed support for Option V, but also expressed some support for Option IV. Ms. Ward stated that Option V should be combined and coordinated with Option IV by involving the Department for the Aging and the Virginia Association of Area Agencies on Aging "and other appropriate state agencies in education, so that constituencies in addition to the aging are served." According to Ms. Ward, home health providers and health plans should be specifically included in Option V. Finally, Ms. Ward stated that "As we implement Option V, we may better determine whether Options II or III, or other alternatives, may be useful in encouraging the use of advance directives. We suggest proceeding first with Option V before making statutory changes."

Virginia Poverty Law Center, Inc.

Steven L. Myers, Executive Director, expressed support for Option IV. Mr. Myers stated that the need for education and information about advance care planning and advance directives "is especially acute among low-income Virginians."

JOINT COMMISSION ON HEALTH CARE

Executive Director

Patrick W. Finnerty

Senior Health Policy Analysts

Joseph J. Hilbert William L. Murray, Ph.D. E. Kim Snead

Office Manager

Mamie V. White





Joint Commission on Health Care Old City Hall 1001 East Broad Street Suite 115 Richmond, Virginia 23219 (804) 786-5445 (804) 786-5538 (FAX)

E-Mail: jchc@leg.state.va.us

Internet Address:

http://legis.state.va.us/jchc/jchchome.htm