REPORT OF THE
JOINT COMMISSION ON HEALTH CARE

Palliative Care Study

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

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Preface

House Joint Resolution 369, which was introduced during the 2000 Session of the General Assembly, directed the Joint Commission on Health Care (JCHC) "in conjunction with the American Cancer Society, Hospice, the Medical Society of Virginia, the Virginia Nurses Association, the Virginia Pharmacists Association, the Hospital and Healthcare Association, and the Virginia Cancer Pain Initiative [to] study the issues involved in palliative care." HJR 369 stated that the following issues should be addressed in completing the study: "(i) identify a central resource for patients and families; (ii) designate a central information source, as well as a training program for health professionals; (iii) identify barriers (access, economic, organizational, ethical, and legal barriers) as well as deficiencies that currently exist in the health care system; and (iv) develop an evaluation plan to assess quality and outcomes of palliative care in order to ensure that the patent and his family are able to maintain the best possible quality of life throughout the course of the disease...." The resolution also called for creating a funding mechanism to carry out the palliative care initiatives.

HJR 369 was not adopted by the General Assembly but was communicated via letter from the Speaker of the House of Delegates to the Joint Commission on Health Care. The Speaker's letter, indicated:

> "The House Rules Committee believes that the issues addressed by the resolution merit review. Therefore the Commission is directed to undertake the study and to submit a written report of its findings and any recommendations to the Governor and to the 2001 Session of the General Assembly."

A copy of this letter and HJR 369, as introduced, are included in Appendix A.

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

- Palliative care is "the branch of medicine that provides active care for people with chronic disease which is not responsive to curative treatment," and has a primary goal to provide comfort and relief from pain and suffering. Recent studies have documented that emphasis on therapeutic care to the exclusion of palliative care has often meant that individuals suffering from chronic and terminal diseases have died in severe and protracted pain, and usually in a hospital setting.

- Palliative care is beginning to receive significant attention in the United States in response to changes in disease management. Unlike the scenario of 100 years ago when life expectancy was less than 50 years with death typically resulting from contracting a communicable disease, today most Americans can expect to live for more than 75 years and to die of a chronic rather than acute disease.
- The fact that medical care has historically emphasized therapeutic care rather than palliative care has meant: (1) medical care curriculum is focused on therapeutic care with few courses related to palliative care being offered, and (2) pain medication and symptom relief are not generally well-understood.
- Nationally few medical and nursing schools require course work on "end of life" issues. These issues receive little coverage in the principal medical texts, and little formal training is offered during residency. An American Medical Association survey of medical schools found that only three percent have a <u>required</u> course on providing care to the dying. An informal survey of Virginia's three academic health centers found that none of the medical schools require a course on palliative care although some courses address topics related to such care. However, all three medical schools offer fourth-year electives in palliative care. The nursing schools in Virginia do not offer courses that are devoted only to palliative care. Although there is currently little opportunity for the <u>practicing</u> health care provider to learn about palliative care, several new programs, most notably the Education of Physicians on End of Life Care or "EPEC" program have been developed.
- Hospice programs are currently the principal providers of palliative care both nationally and in Virginia serving approximately 200,000 people nationally and 7,000 statewide. Hospice allows many terminally ill patients to remain in their homes and to receive costly but necessary pain medication as well as emotional and spiritual support. Medicare pays for 70 percent of hospice care provided in the United States. A 1995 study by the Lewin Group showed that in Virginia, each dollar spent for Medicare hospice services saved $1.19 in medical expenditures that would otherwise have been made.
- Some aspects of palliative care have been addressed in Virginia: in-home hospice services are available, hospice/palliative care units are located within several hospitals, and an intractable pain law and Health-Care Decisions Act have been enacted. However, there is no coordinated program or statewide effort to provide education and support to providers and families. Establishing a state-level palliative care entity could provide coordination to ensure that health care professionals have access to "best practices" information, that patients and their families receive useful information and support, and that information is available

regarding the various palliative care programs throughout the Commonwealth.

- Despite the cost-effectiveness of hospice services, there are few residential and inpatient hospice facilities in Virginia due in part to the fact that there is no statutory provision for licensing hospice beds. This means that providers must be licensed as an assisted living facility, hospital, or nursing home in addition to being licensed to provide hospice services.

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 33 and 34.

Public comments were solicited on the draft report. A summary of the public comments is attached at Appendix C.

On behalf of the Joint Commission on Health Care and its staff, I would like to thank the American Cancer Society, the Virginia Association for Hospices, the Hospice of Northern Virginia, the University of Virginia, Virginia Commonwealth University, Eastern Virginia Medical School, Mary Washington Hospital, the Virginia Cancer Pain Initiative, the Board of Medicine, the Board of Pharmacy, the Virginia Department of Health, the Medical Society of Virginia, the Virginia Association of Health Plans, the Virginia Hospital and Healthcare Association, the Virginia Nurses Association, the Virginia Pharmacists Association, and the other agencies and associations who provided input and information during this study.

Patrick W. Finnerty
Patrick W. Finnerty
Executive Director

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I.
Authority for the Study

House Joint Resolution 369 of the 2000 General Assembly Session directed the Joint Commission on Health Care (JCHC) "in conjunction with the American Cancer Society, Hospice, the Medical Society of Virginia, the Virginia Nurses Association, the Virginia Pharmacists Association, the Hospital and Healthcare Association, and the Virginia Cancer Pain Initiative [to] study the issues involved in palliative care." HJR 369 stated that the following issues should be addressed in completing the study: "(i) identify a central resource for patients and families; (ii) designate a central information source, as well as a training program for health professionals; (iii) identify barriers (access, economic, organizational, ethical, and legal barriers) as well as deficiencies that currently exist in the health care system; and (iv) develop an evaluation plan to assess quality and outcomes of palliative care in order to ensure that the patient and his family are able to maintain the best possible quality of life throughout the course of the disease...." The resolution also calls for creating a funding mechanism to carry out the palliative care initiatives.

HJR 369 was not adopted by the General Assembly but was communicated via letter from the Speaker of the House of Delegates to the Joint Commission on Health Care. A copy of HJR 369 is included in Appendix A. The Speaker's letter, which is included in Appendix A also, indicates:

> "The House Rules Committee believes that the issues addressed by the resolution merit review. Therefore the Commission is directed to undertake the study and to submit a written report of its findings and any recommendations to the Governor and to the 2001 Session of the General Assembly."

Organization of Report

This report is presented in four major sections. This section discusses the authority for the study. Section II provides background information concerning recent developments regarding palliative care. Section III describes a number of barriers to effectively providing palliative care. Section IV provides a series of policy options the Joint Commission on Health Care may wish to consider in addressing the issues raised in this study.

II.
Background

Palliative Care Addresses the Need to Provide Comfort and Relief from Pain and Suffering

Palliative care, as defined by the World Health Organization, is "the branch of medicine that provides active care for people with chronic disease which is not responsive to curative treatment." A primary goal of palliative care is to provide comfort and relief from pain and suffering. The goal of palliative care is distinguished from that of therapeutic care which seeks to cure or slow disease progression. Palliative care may be provided in concert with therapeutic care or proceed when efforts to provide therapeutic care are no longer beneficial.

The need for effective palliative care has increased in recent years, given the remarkable advances in medical research and technology that now allow individuals to live under circumstances that would have been inconceivable not many years ago. The near-elimination of diseases such as smallpox, diphtheria, and cholera means that most Americans will die from chronic diseases such as heart disease and cancer. It also means that a larger proportion of Americans will die at an advanced age. The dying process will also be extended since effective medical treatments for conditions such as infections, kidney failure, and other complications of serious illness and cancer will no longer result in an "earlier" death for patients.

Although medical advances have increased the need for effective palliative care, modern medicine has only recently begun to focus on such care. The primary focus of modern medicine has been the provision of aggressive, therapeutic care in order to prolong life. Medical protocol and reimbursement policies have been designed with this focus in mind. Recent studies have documented that this emphasis on therapeutic care and the exclusion of palliative care has often meant that individuals suffering from chronic and terminal diseases have died in severe and protracted pain.

Several Major Studies Have Documented A Critical Need for Palliative Care

The *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments* (SUPPORT) was the first study in almost a century to identify the perceptions of Americans on dying. The study was funded by the Robert Wood Johnson Foundation and conducted by the Center to Improve Care of the Dying at George Washington University in cooperation with six medical centers around the United States. The study researchers reviewed the care provided between 1989 and 1994 within five medical centers. Included in the study were 9,105 seriously ill patients and 1,176 individuals who were 80 years and older.

The study findings portrayed a disturbing picture of dying in America:

- Of the 4,124 patients who died during the study timeframe, more than half died in the hospital.
- Forty percent of patients were reported to be "in severe pain most or all of the time in the last three days of life."
- Of all patients studied, almost half were either tube-fed, on a ventilator, or received resuscitation.
- Most patients experienced difficulty breathing, 80 percent suffered severe fatigue, and 62 percent "had emotional symptoms severe enough that families thought they were difficult to tolerate."
- Fewer than ten percent of patients received hospice services.

The study authors recommended undertaking a coordinated reform effort which would include: "expanding hospice programs and incorporating hospice concepts into broader programs targeted at persons with disabling, eventually fatal illness...[improving] caregiver education...[measuring] quality of care at the end of life, [and demanding and paying only] for adequate performance."

The Institute of Medicine (IOM) published a subsequent study in 1997, *Approaching Death: Improving Care at the End of Life.* The study used a 12-member committee "of experts in medical and nursing care for chronically and severely ill patients, ethics, quality of care, health policy, health services research, law, economics, social services, and related fields" to determine the state of end-of-life care in America.

The IOM study found that, instead of dying at home surrounded by friends and family, most Americans died in hospitals or nursing homes, isolated during "the final stage of life from the rest of living." And although the awareness of end-of-life issues had been raised following the release of the SUPPORT research, the IOM study committee concluded that "very serious problems" remained. Four broad problem areas were identified:

- inadequate or improper pain management;
- legal, organizational, and economic barriers (primarily related to outdated laws and regulations governing prescription drugs and medical reimbursement which encourage providing tests and interventions rather than supportive services);
- education and training of health care professionals which fails to provide the "knowledge, skills, and attitudes required to care well for the dying patient"; and
- inadequate knowledge and understanding of end of life – "we still know too little about how people die, how they want to die, and how different kinds of physical, emotional, and spiritual care might better serve the dying and those close to them."

In summary, the IOM report noted, "Medicine and public health should continue to help people live long, healthy lives. When medicine can no longer promise an extension of life, people should not fear that their dying will be marked by neglect, care inconsistent with their wishes, or preventable pain and other distress. They should be able to expect the health care system to assure reliable, effective, and humane caregiving."

End-of-Life Initiatives Being Undertaken in Other States

A 1998 report, *State Initiatives in End-of-Life Care,* by the National Conference of State Legislatures (NCSL) and the Center to Improve Care of the Dying at George Washington University, indicated at least 20 states (including Virginia) had established commissions or task forces examining end-of-life care issues. Many of these commissions and task forces concentrated on specific end-of-life issues such as improving pain management approaches, encouraging the use of advance directives, and including palliative care in health care education curriculum.

In Virginia, a major study effort was undertaken by the Joint Subcommittee to Study the Commonwealth's Current Laws and Policies Related to Chronic, Acute and Cancer Pain Management from fiscal years 1995 through 1998. The Joint Subcommittee found many of the same deficiencies in pain management of chronic, acute, and cancer pain as has been discussed earlier by national studies – a lack of physician awareness of proper pain management techniques, laws concerning controlled substances that acted as barriers to effective pain management, and insurance policies that failed to reimburse for most pain management services.

A number of administrative and legislative actions were taken as a result of the Joint Subcommittee's work, including:

- the intractable pain law that allows for higher doses of prescription medication to be provided to relieve pain was clarified and strengthened;
- the Board of Medicine informed regulated professions of the intractable pain law;
- the Medical Society of Virginia (MSV) developed the first guidelines in the nation related to the use of opioids in managing chronic non-cancer pain;
- the Board of Medicine was authorized by the General Assembly to endorse the MSV guidelines for opioid use; and
- Virginia's three medical schools worked on "integrating instruction in pain management" into their curricula.

The joint subcommittee also presented, in cooperation with the Medical Society of Virginia and other sponsors, a conference on pain management which was attended by more than 200 participants.

Interest in End of Life Issues Has Increased Significantly in Recent Years

In the last ten years, a number of patients, families, health care professionals and their organizations have become more interested in and more vocal about the need to address important end-of-life issues. *Last Acts*, a membership organization that is undertaking "a national effort to raise awareness of the need to improve care of the dying" was established in 1996 as a coalition of 72 organizations. *Last Acts* now includes more than 490 national, state and local organizations as "partner members." Similarly, the number of hospice programs has increased to more than 2,200 nationwide since the movement was imported from England in 1974.

Moreover, issues related to the right to die have brought palliative care to the attention of the United States Supreme Court. A 1997 Supreme Court ruling has been interpreted as being very supportive of the right to provide aggressive palliative care. While the Court ruled unanimously that no constitutional right to physician-assisted suicide exists, a majority of the Court members ruled that states must ensure that their laws do not impede the provision of palliative care. One of the issues reviewed by the Supreme Court addressed a lower court ruling that it was inconsistent for a New York state statute to allow physicians to withhold or withdraw life-sustaining treatment while prohibiting physician-assisted suicide. The Supreme Court overturned the lower court opinion and ruled unanimously that states have the right to distinguish between prohibiting physician conduct that is designed to intentionally cause death while allowing physician conduct that is designed to relieve pain and may as a foreseeable consequence hasten the patient's death. This ruling has been interpreted as providing for very aggressive palliative care practices.

The American Bar Association (ABA), has recommended the removal of legal impediments and the support of a right to effective pain and symptom management. A policy resolution adopted by the ABA on July 11, 2000 urges all levels of American government to amend laws which impede "quality pain and symptom management [and]...to support fully the right of individuals suffering from pain to be informed of, choose, and receive effective pain and symptom evaluation, management and ongoing monitoring as part of basic medical care, even if such pain and symptom management may result in analgesic tolerance, physical dependence, or as an unintended consequence shorten the individual's life."

Palliative care will receive national attention in September when a four-part television program *ON OUR OWN TERMS: MOYERS ON DYING* will be shown on public television. In advance of the program, local public television stations across the country are "serving as catalysts to encourage health care professionals, medical institutions, religious leaders, civic organizations, hospice centers, public policy-makers and other community-based groups and interested individuals to participate in community efforts related to end-of-care issues." The television program and associated grass roots activities are expected to "stimulate dialogue and community action on the physical, emotional, psychological, and spiritual issues surrounding end-of-life care." The television series will examine such issues as new ways of approaching death, progress made in palliative care, controlling the circumstances surrounding one's death, and model programs for providing palliative care for individuals who lack insurance coverage and financial resources. A companion web site will also include a variety of end-of-life informational materials including articles, a guide for financing care, and segments from the television program.

III.
Addressing Barriers to Palliative Care

Palliative care, with its emphasis on the relief of pain and suffering, can be seen as an emerging field in medical care in the United States. A century ago, an American could expect to live less than 50 years and had a good chance of dying of a communicable disease. The medical system that developed against this background sought to and has been quite successful in extending life. Today, Americans can expect to live more than 75 years on average and to die of a chronic rather than acute disease.

The medical system in America has been described as "interventionist" and reflective of "a general American unwillingness to accept limits – including aging and death." It is not therefore surprising to find that therapeutic, curative care is primarily taught in medical schools with palliative care just beginning to be addressed. It is not surprising to find that pain medications are not well-understood or that medical reimbursement favors the provision of aggressive, therapeutic interventions rather than pain and symptom management. These propensities however, act as barriers to the development of effective palliative care. Figure 1 summarizes the major barriers that were identified during the course of this study. The extent to which any of these barriers limits the palliative care provided in Virginia varies as noted in the following sections.

Historically, Education and Training on Palliative Care Has Received Little Emphasis

A number of studies have concluded that health care education and training does not adequately address palliative care issues. Historically, medical education has focused on curing disease and prolonging life. Medical education has generally included very little discussion concerning pain management or addressing end-of-life issues. The health care professionals contacted for this study indicated that education and training in palliative care is seriously lacking in Virginia. Several providers talked about having to provide end-of-life training for otherwise experienced doctors and nurses who were going to be working in hospice or palliative care units for the first time. This training was needed because palliative care is not taught or well-understood outside of certain specialty care domains.

Figure 1
Barriers to Effective Palliative Care

- Lack of Emphasis on Palliative Care in Health Care Education and Training
- Under-Treatment of Pain by Physicians
- Patient Misconceptions about Pain Medications
- Special Precautions Related to Dispensing Controlled Substances
- End-of-Life Preferences that Are Often Not Followed
- Eligibility Requirements for Hospice Care that Restrict Access
- Reimbursement Incentives that Favor Therapeutic Rather than Palliative Care
- Insufficient Numbers of Residential and Inpatient Hospice Beds
- No System or "Responsible Party" for Coordinating Palliative Care in Virginia

Source: JCHC staff analysis.

According to a 1998 survey conducted by the American Medical Association (AMA), only four of 126 American medical schools required students to complete a course on providing care to the dying. The AMA study indicated:

- less than five percent of medical schools required students to take even one course specifically on palliative care;
- 39 percent of medical schools offered a course specific to palliative care issues as an elective; and
- 96 percent of medical schools included some discussion of death and dying as part of an existing course.

A study in 1995 of residency programs in the United States, reported in a *Journal of the American Medical Association* article, found that residents and fellows cared for an average of 28 dying patients per year. Despite this relatively high level of contact with dying patients, the study found that within the 1,068 residency programs reviewed, 15 percent offered no formal training in end-of-life care, nine percent offered a hospice course only as an elective, and only eight percent had a required hospice rotation.

In 1999, a review of four widely-used medical textbooks was conducted by the Center to Improve Care of the Dying at George

Washington University. The study concluded that the issue of how to care for dying patients was generally not addressed and that of "the nine issues that are important to good care of the dying, few were addressed for any illnesses covered in the textbooks. Symptom management advice is given only for three illnesses in one textbook – the other illnesses and textbooks gave no useful information, even on pain."

General Consensus Appears to Exist on Guidelines for What Should Be Included within Palliative Care Education

Many of the recommendations in the current literature arise out of the National Consensus Conference on Medical Education for Care Near the End-of-Life sponsored by the Open Society Institute's Project Death in America and the Robert Wood Johnson Foundation. The consensus recommendations are based on generally accepted principles of medical ethics, expert opinion, and studies of the efficacy of treatments for common problems at the end of life such as pain, shortness of breath, and depression.

Recommendations for palliative care education indicate that the care of the dying patient and their family should be a core professional task and that medical and nursing schools have a responsibility to educate accordingly. The specific areas to be addressed include communication skills, pain management, provision of good quality home and hospice care, eliciting patients' wishes, understanding ethical issues, learning to work with interdisciplinary teams and acknowledging one's own opinions and attitudes regarding death and dying. From the beginning of professional school, health care providers need to be taught that death is not always a bad outcome or a failure. Since these attitudes, knowledge, and skills are best taught using seminars and workshops, it is recommended that clinical practice include hands-on experiences with patients at the end-of-life.

The Curricula of Virginia's Medical Schools Do Not Require a Course on Palliative or End-of-Life Care

Informal surveys were completed for this study – first of the instruction provided by Virginia's medical and nursing schools, and second of the residency practices within internal medicine, pediatrics and family practice. These surveys indicate that palliative care is considered to be an important issue and that curriculum changes are being planned to address existing deficiencies. However, most of the respondents feel that barriers to improving palliative care included time restrictions within an already crowded curriculum, an over-extended teaching faculty, and financial barriers to providing effective palliative care.

In terms of medical school curricula, none of the medical schools currently offer a required course specifically on palliative care or end of life issues. Topics related to palliative care such as ethics and communication skills are covered in some detail during the first and second years of medical school. Exposure to palliative care training during the third year of medical school varies depending on the specialty rotation that is followed and the preference of the faculty member. All of the schools offer fourth-year electives related to palliative care.

Medical residency experiences differ based on the medical school attended and the resident's chosen specialty. Virginia Commonwealth University/Medical College of Virginia (VCU/MCV) and the University of Virginia (UVA) each has a palliative care consult team and Eastern Virginia Medical School (EVMS) is in the process of establishing one. VCU/MCV has an adult palliative care unit that was only recently established so residency rotations have not been completed on the unit. UVA has an inpatient hospice unit and internal medicine residents complete a rotation on the unit. Within pediatrics there appears to be less focused education on palliative care, although all of the residents rotate on hematology and oncology units and in the pediatric intensive care unit where they receive a more concentrated hands-on experience in palliative care. VCU/MCV also has a pediatric, compassionate care team, but currently there is no resident or student exposure to that team. Most family practice residents have an opportunity to participate in the care of dying patients, and some programs have required rotations with a local hospice.

Education and Training in Palliative Care for Nurses Has Also Historically Received Less Emphasis than Therapeutic Care

The City of Hope National Medical Center surveyed 2,300 nurses about the end-of-life training they had received. In rating nine different areas of nurse training, training provided in pain management, general end-of-life care, and needs of caregivers were rated as the weakest areas. Only 13 percent of the nurses considered training they had received on end-of-life issues to be "very adequate." Nevertheless, 66 percent of responding nurses indicated that the provision of end-of-life care "is better than it was five years ago."

Several nursing administrators were interviewed regarding the end-of-life curriculum and practical experience provided in nursing schools in Virginia. The administrators indicated that there were no classes offered solely on palliative care although palliative care is addressed during clinical rotations. In general, respondents reported a need for improved training, particularly with respect to pain management.

Relatively Little Continuing Medical Education in Palliative Care Has Been Offered

For physicians who have graduated from medical school without being provided a strong foundation in palliative care, there are relatively few continuing medical education (CME) courses that are currently available. For example, no palliative care courses are offered by the American Association of Pediatrics or the American Academy of Family Physicians. The American Medical Association (AMA), in cooperation with the Robert Wood Johnson Foundation, has developed and continues to offer a 2.5 day program called Education of Physicians on End-of-Life Care (EPEC). Examples of subjects taught during the EPEC course include talking to patients and families about terminal illness; recognizing depression; using drugs to relieve shortness of breath, nausea, and other symptoms; recognizing the physical changes that indicate death is near; and assisting with advance care planning. The program follows a "teach the teacher" format which allows participants to also learn how to teach others about end-of-life care. The course has generally received favorable feedback although there is concern that 2.5 days is too lengthy a course for most busy practitioners to attend. Several physicians in Virginia have attended the course and reported implementing many of the EPEC materials within their residency programs in internal medicine and family practice.

Several palliative care experts indicated that traditional continuing medical education offerings are not the most effective way to develop the knowledge and skills of primary care providers for end-of-life care. Instead, they suggested establishing a number of centers of excellence around the Commonwealth to provide short courses on a variety of specific palliative care issues. It was suggested that these centers would allow for establishing relationships with health care providers throughout each service area which would be effective in promoting the concept of palliative care.

Pain Is Often Undertreated in Individuals Suffering from Terminal Illnesses

A number of studies have found that individuals at the end-of-life are often in severe pain and discomfort that is undertreated or completely untreated. The 1995 SUPPORT report indicated that approximately 50 percent of conscious patients with terminal illnesses reported to their families that they were in moderate to severe pain during the last days of their lives. A study reported in 1999, in the *Journal of the American Medical Association,* reported that "39 percent of elderly cancer patients in nursing homes experienced daily pain, but only 12 percent received treatment" for that pain. This is despite the fact that there are a variety of effective treatments for severe, chronic pain.

The most commonly identified reasons for physicians undertreating pain include being unfamiliar with effective pain management techniques, being afraid of investigation or prosecution for prescribing high doses, and being unaware of the level of pain that patients suffer. As noted previously, many physicians, particularly those who are not specialists in a field which treats a number of terminally ill patients, have not been taught about pain and symptom management. These physicians may not realize the high doses that would be needed to relieve pain or may be uncomfortable prescribing such high doses.

The most common reason reported by physicians for not adequately treating pain, has been the fear of being investigated for prescribing high doses of controlled substances. Controlled substances such as opioids (including morphine) are medications which are either derivatives or work like derivatives of opium. These opioids are often very effective in addressing severe, chronic pain but with continued use, patients typically develop tolerance to the medication and dosage may need to be continually increased. Dr. Joanne Lynn, a renowned expert on pain management and director of the Center to Improve Care of the Dying at George Washington University, notes that most opioids have "no dosage ceiling, and some patients need 1,000 mg or more every hour to reduce the pain to a level [at which] they can function."

Several studies have indicated that physicians tend to underestimate the severity of pain and other symptoms that patients suffer. In one study, interviews were completed with parents of children who died of cancer at Children's Hospital in Boston between 1990 and 1997. These interviews revealed that physicians were much less likely than the parents to report that the children suffered from such symptoms as "fatigue, poor appetite, constipation, and diarrhea." Forty-nine percent of the parents reported that their children "suffered 'a lot' or 'a great deal' from at least one symptom in their last month of life, most commonly pain, fatigue, or dyspnea [labored breathing]." In this study, it was noted that when pain management was undertaken, it was only effective in 27 percent of the attempts.

Some states have instituted additional controls over prescriptions of controlled substances, such as requiring the filing of special forms or triplicate copies of prescriptions. These controls often have the effect of discouraging physicians from prescribing controlled substances to avoid the additional paperwork and the feeling of being monitored.

Virginia Has Enacted Laws Designed to Allow Physicians to Prescribe High Dosages of Pain Medication as Needed

In contrast with actions taken in some states, Virginia has taken several actions to enhance the ability to appropriately prescribe and dispense pain medication particularly for those in intractable pain. First, statutory protections were added to ensure that "excess dosages" of pain medication may be prescribed, dispensed and administered as needed for appropriate patients. Section 54.1-2971.01 reads:

> "a physician may prescribe a dosage of a pain-relieving agent in excess of the recommended dosage upon certifying the medical necessity for the excess dosage in the patient's medical record. Any practitioner who prescribes, dispenses or administers an excess dosage in accordance with this section and § 54.1-3408.1 shall not be in violation of the provision of this title because of such excess dosage, if such excess dosage is prescribed, dispensed or administered in good faith for recognized medicinal or therapeutic purposes."

Section 54.1-3408.1 contains very similar language, indicating that the provisions apply to prescriptions for patients with intractable pain. Second, the Board of Medicine alerted regulated medical professions about these statutory changes. Third, the Medical Society of Virginia developed guidelines on the use of opioids to assist physicians in addressing their patients' severe, chronic pain. These guidelines were communicated through a Board of Medicine newsletter during Spring 1998.

Several oncologists indicated that because of the statutory protections and guidelines that are in place, they do not consider regulatory investigation to be a primary reason that physicians in Virginia would fail to prescribe needed pain medication. Despite the efforts of the Medical Society of Virginia and the Board of Medicine to inform physicians of statutory protections, it is not clear that physicians who would only occasionally prescribe these types of pain medications would be familiar with those protections.

New Accreditation Standards Will Include Pain and Symptom Management

In an effort to address the issue of pain and symptom management, the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) will include new standards in its 2000-2001 standards manuals for accreditation. The new standards require health care organizations to:

- "Recognize the right of patients to appropriate assessment and management of pain.
- Assess pain in all patients.
- Record the results of the assessment in a way that facilitates regular assessment and follow up.
- Educate relevant providers in pain assessment and management.
- Determine the competency in pain assessment and management during the orientation of all new clinical staff.
- Establish policies and procedures which support appropriate prescription or ordering of pain medications.
- Assure that pain does not interfere with participation in rehabilitation, and educate patients and their families about the importance of effective pain management.
- Include patients' needs for symptom management in the discharge planning process.
- Collect data to monitor the appropriateness and effectiveness of pain management."

JCAHO has also approved pain as a fifth vital sign to be monitored along with temperature, blood pressure, pulse, and respiration.

Patient Misconceptions about Pain Medication Also Result in Inadequate Management of Pain and Symptoms

Patients are also sometimes reluctant to take pain medication, such as opioids, believing it is a sign of weakness or moral failure to take them. Opioids are narcotics with all of the negative connotations associated with both using and prescribing them. Patients (and sometimes physicians) confuse the concepts of addiction and physical dependence. Pain management experts make the following distinction:

> "*Addiction* – or psychological dependence – is a behavioral disorder characterized by compulsive seeking of mood-altering drugs and continued use despite harm. *Physical dependence* is a normal response of the body to a substance characterized by signs of withdrawal if drug use is stopped."

Pain management experts note that "prescribed appropriately and knowledgeably [opioids] don't have the...effects of stupor or addiction" implied by their classification as narcotics. While physical dependence frequently occurs with opioid therapy, experts note that actual addiction is rare.

Patients may also be reluctant to tell their physicians just how much pain they are in and may believe that it is best to take as little pain medication as possible. Many pain management experts believe that effective pain and symptom management actually extends rather than shortens life, particularly when it is introduced early in the treatment process. Providing effective pain and symptom management may allow a patient to begin or continue treatment that would be otherwise intolerable. Even when therapeutic efforts are no longer beneficial, effective pain and symptom management allows individuals to focus on something other than the pain or discomfort they would otherwise experience.

Special Precautions Taken in Dispensing Controlled Substances Can Make it More Difficult for Patients to Receive Medication Needed to Manage Pain

Pharmacists play a crucial role related to the provision of palliative care. Pharmacists' expertise relates to all aspects of medication and they can play an important role in advising physicians regarding pain medication and in talking with patients about how well pain medication is working. To be able to do this, pharmacists like other health care providers need to understand palliative care and be comfortable with dispensing controlled substances. Special precautions that are taken when dispensing controlled substances can make it more difficult for patients to receive needed pain medication. The problems that were identified included:

- the need for the pharmacist to call about a prescription for an unusually high dosage of a controlled substance if the patient and the nature of the patient's illness are not familiar to the pharmacist;
- a reluctance to stock controlled substances particularly on the part of some rural pharmacies and indigent care clinics; and
- restrictions on sending prescriptions for controlled substances by facsimile unless the patient is housed in a nursing home, is a home infusion patient, or is served by a hospice.

It is clear that pharmacists must be diligent in ensuring that prescriptions that appear to be incorrectly written or may be forged are verified and corrected as needed. However, a review of prescription-related deaths in North Carolina suggest too much emphasis may be placed on controlled substances. Since 1992, the North Carolina Board of Pharmacy has required reporting of all deaths believed to have been related to the taking of prescription medication. A review of the deaths, which occurred from 1992 through October indicated, that only 18 percent of the 162 deaths were related to taking a controlled substance. Moreover, while the number of deaths related to prescription-taking had been increasing over time, the number related to controlled substances had been decreasing. Only 11 percent of deaths that occurred in 1998 and most of 1999 were attributed to the use of controlled substances. Palliative care experts indicate that controlled substances, even at high doses are quite safe if a patient has built up a tolerance over time.

One area of concern relates to the converting of controlled substances from pill to another form such as liquid or skin patch when patients are no longer able to swallow pills. Palliative care experts report that physicians and pharmacists are often unfamiliar with making those conversions which can result in an incorrect dose of the controlled substance being provided. This can result in either inadequate pain management for the patient or a dangerously high dose of medication being provided.

One potential means of increasing the comfort-level of both physicians and pharmacists related to prescribing and dispensing high doses of controlled substances involves having an Internet-based registry of individuals who require high doses of controlled substances on an ongoing basis to control pain. Patients' participation in the registry would be completely voluntary. Including patients on the registry would allow physicians and pharmacists to document the need for the medication. It would also provide pharmacists a means of verifying medication dosages other than personally talking with prescribing physicians which can be a time-consuming endeavor.

Another identified option involved including information important to palliative care on a "list serve" to pharmacists who have on-line capabilities. A "list serve" is an electronic mail function that allows all listed individuals to receive messages through electronic mail. A palliative care list serve could be established to provide such information as findings of the latest research regarding symptom management, dosing equivalents for converting pain medication, and information about new drugs and proper dosages to relieve pain. It was suggested that the list serve could be an ongoing graduate project for pharmacy students.

Patient Wishes Regarding End-of-Life Care Are Not Always Known or Followed Raising Legal and Ethical Issues

The Federal Patient Self-Determination Act (PSDA) was enacted in 1990, following the U. S. Supreme Court's decision in *Cruzan vs. Director, Missouri Department of Health.* The Supreme Court decision "simultaneously upheld the right of individuals to make decisions regarding the termination of life-sustaining treatment and the right of states to ensure the reliability of those decisions through reasonable regulations." As noted in the JCHC study on advance directives, PSDA requires hospitals, skilled nursing facilities, hospice programs, home health agencies, and health maintenance organizations that participate in Medicare and Medicaid to:

- provide patients with written information about their rights under state law to make decisions regarding 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 medical record whether or not the individual has executed an advance directive;
- ensure compliance with the requirements of state law respecting advance directives; and
- provide for education for staff and the community on issues concerning advance directives.

Despite federal efforts, such as PSDA, studies indicate that many health care providers continue to be uncomfortable discussing end-of-life issues with patients or their families. There is also reluctance on the part of a number of physicians to discontinue therapeutic intervention notwithstanding the stated wishes of patients or their families. The 1995 SUPPORT report found that "half the physicians did not respect or know about patients' advance directives, the majority of do-not-resuscitate orders were not instituted until 24 hours before the patients' deaths, and most soberingly, 40 percent of patients had severe and potentially treatable pain for more than several days before they died."

Moreover, a number of studies have found that relatively few Americans have executed advance directives or made any formal provisions for determining their end-of-life care in case of incapacitation. The studies indicate that public misperceptions about advance directives including the fear of abandonment with no provision for pain and symptom management may significantly affect this issue. In the absence of advance directives to provide direction, patients are often subjected to aggressive but ineffectual medical procedures which prolong life without contributing to the quality of life.

The question of what constitutes "life-sustaining treatment" also raises legal and ethical issues. There appears to be general agreement on certain protocols such as providing for Do Not Resuscitate Orders and the withdrawing of artificial life support. Other protocols, such as the withholding of food and providing for terminal sedation when no other means of pain control is available, are somewhat less universally accepted. In Virginia, the "Health Care Decisions Act" (*Code of Virginia* Title 54.1, Chapter 29, Article 8) provides physicians with relatively wide latitude in issuing a Durable Do Not Resuscitate Order and in withholding or withdrawing a "life-prolonging procedure" or "life-sustaining care." These two terms are statutorily defined as follows:

> "'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."
>
> "'Life-sustaining care' means any ongoing medical treatment that utilizes mechanical or other artificial means to sustain, restore or supplant a spontaneous vital function, including hydration, nutrition, maintenance medication, and cardiopulmonary resuscitation."

The "Health Care Decisions Act" clearly states that the provisions of the Act are not meant "to condone, authorize or approve mercy killing or euthanasia, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying."

Hospice Programs Are Currently the Principal Providers of Palliative Care

While palliative care has not been widely embraced within the health care field in general, the provision of palliative care is a cornerstone of the hospice movement. The hospice movement was in part a response to the increasing number of patients who were dying in hospitals rather than in their homes and the fact that these hospitals were not appropriately managing pain or providing comfort and support to dying patients. Hospice programs in the United States serve approximately 200,000 people each year.

Although many people think of hospice programs as a type of end-of-life care that is provided on an inpatient basis within a unit of a hospital, nursing home, or freestanding facility, hospice care is actually more often provided on an outpatient basis allowing patients to remain in their homes. Approximately 80 percent of the hospice care that is provided in the United States is provided in the patient's residence (which may be the home or other place of residence such as an assisted living or nursing facility). This type of outpatient hospice care involves "an organization or program that provides, arranges, and advises on a wide range of medical and supportive services for dying patients, their families and friends."

Medicare pays for 70 percent of the hospice care provided in the United States. The Medicare hospice program was created in 1983. The Medicaid hospice program was established in 1986 and is patterned after the Medicare hospice program. Medicare and Medicaid reimburse hospice programs on a capitated per-diem basis. The amount of the reimbursement varies slightly on the basis of geographic location. In Virginia, the reimbursement for at-home or respite care is about $90 to $100 per day, while the reimbursement for inpatient care is $513 to $638 per day. Continuous home care, a fourth type of hospice care, is only provided after a crisis situation with the patient has been documented. Continuous home care is reimbursed on an hourly basis and is paid at 1/24th of the per diem rate for the geographic area.

In addition to providing physician and nursing services, Medicare and Medicaid provide for a variety of services including home health care, physical and speech therapy, and counseling. Hospice services must be available on a 24-hour per day, seven-day per week basis. Under Medicare and Medicaid regulations, all expenses (including prescription costs and medical appliances and supplies) that are related to a patient's terminal disease must be covered under the per-diem payment. Prescriptions and other medical expenses related to any ancillary conditions such as diabetes or high blood pressure would not be the responsibility of the hospice program. For many terminally ill individuals, hospice care allows them to both remain in their home and to receive costly but necessary pain medication.

More Individuals Could Benefit from Palliative Care if They Could Access Appropriate Services

Many individuals who could benefit from palliative care services are not able to access those services. First, there are relatively few programs, other than hospice services, that emphasize palliative care rather than aggressive curative care. Second, even within hospice programs, there are barriers to accessing services. Medicare and Medicaid, the primary payors for hospice services, have a number of eligibility requirements and informed indicators that patients are expected to meet to receive services. A number of private insurance policies also include a hospice care benefit but these policies often require policyholders to meet many of the same eligibility criteria as the federal programs. Figure 2 summarizes five specific Medicare and Medicaid eligibility requirements indicators that restrict access to hospice services.

Figure 2
Medicare/Medicaid Eligibility Requirements Indicators Restrict Access to Hospice Services

Eligibility Requirement	Effect of Requirement
The individual must be suffering from a terminal illness.	Excludes individuals who need palliative care to address chronic pain or debilitating symptoms from a disease or disorder that is not life-threatening.
A physician must certify that the patient is expected to have less than six months to live if his or her disease follows its expected course.	For many diseases, it is difficult to predict how long a person can be reasonably expected to live.
The individual is expected to become more debilitated over time indicating that the disease is advancing.	Excludes individuals who experience remission or whose disease does not markedly worsen over time.
Being homebound is sometimes used as an indicator that the individual is ill enough to require hospice services.	Excludes individuals who may be able to leave their home for short periods of time.
The individual must agree not to undergo therapeutic or curative measures to prolong life.	Excludes individuals who may not be ready to forego all available therapeutic measures. There is no definitive list of what treatment regimens are considered to be therapeutic in nature.

Source: JCHC staff analysis.

Most of the eligibility restrictions are in keeping with the end-of-life focus of hospice care. However, since hospice programs are often the only palliative care option available, these restrictions prevent many individuals – who are not expected to die within six months or who suffer from chronic pain or debilitating symptoms from diseases that are not terminal – from accessing any effective care.

For many diseases, such as congestive heart failure, chronic obstructive pulmonary disease, and end-stage liver disease, the progression of the disease is not predictable. A review of the patients suffering from the aforementioned diseases included in the 1995 SUPPORT study revealed that 70 percent were alive after six months in the program. This is despite the fact that those patients had been diagnosed as being terminal or as having less than six months to live and were all quite ill. This illustrates how difficult it is to determine with any precision when a particular patient may be expected to have no more than six months to live.

Several pediatric oncologists in Virginia reported that hospice requirements are especially problematic when trying to access care for children. Since children often live longer with their disease, needed palliative care services may be unavailable for months or even years until the children are sick enough to justify a six-month survival prognosis. Children often benefit from attending school even if only for a few hours a day but this violates the informal requirement for the patient to be home bound. Physicians are also unwilling to forego aggressive interventions given the high success rates with therapy for children.

Attitudinal studies also reveal that differences in how people of various races view terminal illness can be a barrier to accessing palliative care. The chief of pain and palliative care services at New York's Memorial Sloan-Kettering Cancer Center maintains that many African Americans refuse palliative care believing that it would mean that all hope is gone and no life-saving efforts would be attempted. He indicated that "many blacks worry doctors will not respect their personal and cultural values when they are dying," and that "their race and socioeconomic status make them more 'disposable' and that treatment decisions will reflect that attitude."

Studies Have Shown that Hospice Services Can Be a Cost-Effective Alternative to Therapeutic Care

Therapeutic care provided at the end of life can be quite costly particularly when a chronic illness is involved. A 1993 study published in the *New England Journal of Medicine* found that approximately 30 percent of Medicare benefits are expended during the last year of the patient's life. Nearly half of those expenditures were made during the last two months of life. In studies reported by the National Hospice Organization, it was shown that hospice care usually replaces rather than supplements therapeutic care of terminally ill patients and that hospice coverage does not increase the overall cost of end-of-life medical care.

In 1995, the Lewin Group, reported on a study which compared Virginia's Medicare costs for cancer patients who used hospice services and those who did not. The Medicare patients included in the study died between July and December of 1992. That study reported that each $1.00 spent on Medicare hospice coverage "saved $1.19 in expenditures for other types of care."

Virginia Law Requires that Health Insurance Policies and Health Maintenance Organization Plans Include Hospice Services

As of July 1, 1999, newly issued or renewed health insurance policies and health maintenance organization (HMO) plans are statutorily required to include coverage for hospice services. Section 38.2-3418.11.A of the *Code of Virginia* reads:

> "each insurer proposing to issue individual or group accident and sickness insurance policies providing hospital, medical and surgical, or major medical coverage on an expense-incurred basis; each corporation providing individual or group accident and sickness subscription contracts; and each health maintenance organization providing a health care plan for health care services shall provide coverage for hospice services under such policy, contract or plan delivered, issued for delivery or renewed in this Commonwealth on and after July 1, 1999."

The way in which the "hospice services," "individuals with a terminal illness," and "palliative care" are defined in § 38.2-3418.11.B establishes requirements for insurers and HMO providers that are consistent with the hospice coverage provided by Medicare. Thus, Virginia residents who have a terminal disease "whose medical prognosis is death within six months, and who elect to receive palliative care rather than curative care" are eligible for hospice services under health insurance policies and HMO plans. Section 38.2-3418.11.D indicates that the statutory language does not prohibit the provision of hospice services to individuals who are not terminally ill or who may be expected to live for longer than six months. (A copy of *Code of Virginia* § 38.2-3418.11 is included as Appendix B.)

Although the *Code of Virginia* was amended effective July 1999, the bill was referred to the Special Advisory Commission on Mandated Health Insurance Benefits to be reviewed following the 1999 Session of the General Assembly. The Advisory Commission's study indicated the following:

- As of August 1, 1999, 73 percent or 11 of the 15 industry respondents, to the Commission's staff survey, reported providing the mandated hospice coverage as part of their standard contract.

- Industry estimates of the premiums associated with mandatory hospice services ranged from $0.02 to $3.00 per month for individual policies and from $0.03 to $3.00 per month for group policies.
- The mandated hospice coverage was not expected to (1) affect the cost of providing health care during the following five years, or (2) increase the "inappropriate use" of hospice care, or (3) significantly influence the number of hospice providers in the short-term although some increase might occur in the longer term.
- Information supplied by the National Insurance Law Service, indicated that three other states (Massachusetts, Kentucky, and Nevada) mandate hospice coverage and six states (Colorado, Maryland, Michigan, Minnesota, New York, and Washington) mandate the provision of "optional coverage for hospice care."

The Virginia Association for Hospices both spoke and wrote in favor of the hospice legislation and no comments were received in opposition to the bill. The Advisory Commission voted 8-0, with one abstention, to recommend mandating hospice care coverage.

Third-Party Reimbursement Encourages the Provision of Therapeutic Treatments Rather than Palliative Care Services

Third-party payors of medical care, including Medicare, Medicaid and most private insurance companies, encourage the types of treatments involved in therapeutic care than in palliative care through their reimbursement policies. This is first because reimbursement for performing tests and therapeutic procedures is higher than the typical techniques used for providing pain and symptom relief. A Virginia oncologist noted that his reimbursement for providing chemotherapy represents two-thirds of his income. Anytime he foregoes providing chemotherapy in favor of another treatment or palliative care option, he knows the reimbursement will be reduced accordingly. The second problem relates to the inability to receive any reimbursement for many of the palliative care services that need to be provided. Hospice programs for example, typically employ social workers, chaplains, and other non-medical staff who provide emotional and spiritual support that is often so important for patients and families. Under most third-party reimbursement systems, there would be no method for reporting these types of expenses when palliative care is provided outside of a hospice program.

Because third-party reimbursement for palliative care is relatively low, actual palliative care costs often exceed the reimbursement that is provided. Thirty percent of families interviewed for SUPPORT in 1995 reported they had used most, if not all of their savings to provide care for their dying loved ones. Although some of the financial problems resulted from having to quit jobs to stay at home to provide care, many of the problems resulted from the expense of the unreimbursed care. Hospice providers have reported similar problems with paying for the palliative care that is needed within the per-diem reimbursement they are provided.

One hospice administrator in Virginia reported the following estimated costs for some of the most effective pain and symptom management therapies that are often used in hospice care:

- Zofran, medication for nausea costs $23 per pill or $100 per day;
- Duragesic, a skin patch that provides ongoing pain relief for two to three days costs $36 per patch;
- intravenous therapies vary in cost according to the fluid being provided but can cost as much as $58 per day;
- one special air bed used for patients that have painful skin lesions can cost as much as $3,000 per patient to rent.

These medications would be provided by the hospice as part of its per-diem services. The hospice administrator wrote: "When you realize that most patients are receiving several drugs and require a variety of [durable medical equipment] simultaneously to control their symptoms, it quickly becomes clear that hospice reimbursement most often fails to cover the cost of caring for our patients." For individuals, who need these types of palliative care medications and supplies but do not have hospice care, the cost often exceeds the individual's ability to purchase them.

According to a representative of the Virginia Association of Hospices, hospice reimbursement is supposed to be designed so that higher costs of care – which typically occur when an individual is first accepted into the program and during the last weeks of that individual's life – will be spread over a number of months of less expensive care. The representative reported that this is typically not occurring however considering that the average length of stay in Virginia is 60 days.

Reimbursement for Hospice Care Is Being Evaluated at the Federal Level

There are developments on the federal level that indicate that the reimbursement provided for palliative care is being reexamined. In October 1996, the Health Care Financing Administration (HCFA) approved a diagnostic code for hospitals to use in reporting palliative care interventions. In addition to providing hospitals with a means of reporting palliative care services, the code will enable HCFA to determine whether there is a need to create a diagnosis-related group (DRG) that specifically accounts for end-of-life care. The development of a palliative care DRG has the potential to provide more appropriate reimbursement of the care and support that is provided.

A need to improve hospice reimbursement was presented during a special hearing on Improving End-of-Life Care held by the Senate Special Committee on Aging. A representative of the National Hospice and Palliative Care Organization testified during the hearing held July 17, 2000 that the Medicare reimbursement rate is inadequate. The representative referred to interim findings from a cost study that determined "patients are enrolling in hospice closer to the time of death and require more intense and frequent services than was required when Medicare originally established reimbursement rates." The study, which was completed by an independent actuary and consulting firm, found that average length of stay on a nationwide basis has been decreasing and is currently 40 days.

There Is No Provision in Virginia Statute to License Hospice Beds Which Has Contributed to a Shortage of Such Beds

Although the hospice philosophy emphasizes that the best quality of life almost always involves remaining in the home with family members as caregivers, that type of care is not always possible. A number of states allow for the licensing of hospice beds as either residential or inpatient beds depending on the types of services that will need to be provided. Residential hospice facilities provide a home-like residence for patients who do not have a caregiver within the home. Inpatient hospice beds are used to provide specialized (and typically short-term) care for the patient or to provide the caregivers a respite by keeping and caring for the patient for them. (Medicare and Medicaid will pay for inpatient hospice care for not more than five consecutive days in order to provide a respite for caregivers. Combined inpatient and respite care days cannot account for more than 20 percent of all Medicaid-paid hospice days in any one year.)

In Virginia, there is no provision for licensing hospice beds either as residential or inpatient beds. Consequently, in order to have a specialized facility, the hospice would need to be licensed both to provide hospice services and as an assisted living facility for residential beds or as a nursing home or hospital to provide inpatient beds. If a hospice decides to establish or expand a free-standing in-patient facility, the hospice must first receive approval under the Certificate of Public Need (COPN) program.

Hospice representatives indicated although there is a need for both residential and inpatient hospice beds in Virginia, having to meet multiple licensing requirements has been a significant barrier to development. The Virginia Association for Hospices reported being aware of two residential facilities and one inpatient facility in Virginia. An administrator with the Hospice of Northern Virginia, which operates the one free-standing inpatient hospice facility indicated that the shortage of such beds is one of their "most pressing problems." The administrator indicated that the patients who need inpatient care are "acutely ill, with symptoms or a degree of illness that meant they must receive specialized, round-the-clock care." The free-standing facility which contains 15 beds was reported to be continually full and that often a waiting list for admission has to be maintained. The administrator noted further: "Although many hospices in more rural parts of the Commonwealth are able to contract with local hospitals to provide hospice services within existing hospital facilities, that is not possible for us because of a lack of capacity at area hospitals." The Hospice of Northern Virginia intends to apply for COPN approval to expand the number of beds in its free-standing facility. That application will be considered beginning next December in conjunction with all other applications to expand existing hospitals. (The Joint Commission on Health Care currently is developing a plan to eliminate the Certificate of Public Need program as directed by Senate Bill 337 of the 2000 Session of the General Assembly.)

The Virginia Department of Health (VDH) is in the process of revising its licensing regulations for hospice services that are provided with the patient's residence. A department official indicated that there are no plans to develop licensing requirements of residential or inpatient hospice beds since VDH has no statutory authority to provide such licenses.

Virginia Has Addressed Aspects of Palliative Care But a Systematic Approach Is Not In Place

During the last decade, aspects of palliative care have been addressed in Virginia allowing for valuable knowledge in end-of-life care to be gained. Virginia has licensed hospice services since 1991 and approximately 7,000 patients are served annually by 50 licensed hospice organizations. Virginia has one free-standing hospice facility, and at least three hospice/palliative care units within hospitals. Since July 1999, health insurance policies and HMO plans have been required to cover hospice services. In addition, Virginia has been proactive in the development of advance directives and Durable Do Not Resuscitate Orders within the "Health Care Decisions Act." The Joint Subcommittee to Study the Commonwealth's Current Laws and Policies Related to Chronic, Acute and Cancer Pain Management focused attention on the issue of pain management, which led to important legislative and administrative actions.

Despite these actions, there is no organized or coordinated system of palliative care in Virginia. This was reflected in the fact that no broad-based coalition of interested entities could be assembled to apply for partnership grant funding from the Robert Wood Johnson (RWJ) Foundation. In 1999, the RWJ Foundation established its national grant program *Community-State Partnerships to Improve End-of-Life Care.* The program "supports statewide coalitions that are broadly based, multi-disciplinary, and multi-dimensional, with strong internal leadership and access to state policy-makers." Seventeen states, other than Virginia, were awarded state-community partnership grants last February by the RWJ Foundation. The Foundation sponsors another national program, *Promoting Excellence in End-of-Life Care,* that "awarded 24 three-year grants averaging $450,000 to innovative programs of national significance aimed at improving access to comprehensive palliative care across a range of clinical settings."

Representatives of the Virginia Association for Hospices met with representatives from several state and private organizations but they were unable to identify or establish a coalition to successfully compete for a community-state partnership grant. Without this type of broad-based coalition, it will also be difficult for Virginia to take a systematic approach to improving the availability and quality of palliative care.

Innovative Palliative Care Programs Have Been Developed in Virginia That Could Assist in Developing a System of Care

While no systematic approach has been taken, several newly-developed and innovative palliative care programs were identified during the course of the study. These programs, which included two palliative care hospital units and an in-home palliative care program, will expand the options available for effective end-of-life care.

Palliative care units were established at Mary Washington Hospital and at Virginia Commonwealth University/Medical College of Virginia earlier this spring. The unit at Mary Washington has eight beds within the oncology unit. The unit at VCU/MCV contains 11 beds. For patients on both units, the expected length of hospital stay is four to five days. Both palliative care units accept acute care patients interested in focusing on pain management and emotional support.

Another innovative palliative care program, established in 1999 and funded by the Arlington Health Foundation, allows individuals with life-threatening illnesses to receive medical services and emotional support in their homes. The grant program is administered by Hospice of Northern Virginia and serves individuals who do not qualify for hospice care services. The fact that program participants do not have to meet hospice eligibility requirements (such as being homebound or foregoing all therapeutic interventions) allows participants to access palliative care services (in addition to any desired curative care) earlier in their disease progression. Fifty-two individuals ranging in age from four months to 64 years have received services. An independent evaluation of the grant program is being completed this summer. The evaluation will examine several quality of life indicators, the types of services provided, and associated costs.

Innovative educational programs are also being developed. The American Oncologists Association is preparing to release a pain management curriculum that will include approximately 30 topics such as pain medication, relieving breathlessness, and relieving sleeplessness. The American Association of Colleges of Nursing is working with the Los Angeles-based City of Hope Cancer Center to develop an educational program for nurses on end-of-life care. The project is being funded by the Robert Wood Johnson Foundation and intends to follow a "train the trainer" format to allow for broad dissemination of the training. MKHP Associates, a research organization in Northern Virginia has developed a palliative care curriculum for training paraprofessionals, volunteers, and family caregivers. Training has already been provided for 264 staff within health care organizations in Virginia, Maryland, and the District of Columbia, and for 80 health care providers through distance-education telecasts to community colleges around Virginia. These types of curricula could be very useful in developing resource centers for palliative care. These centers could provide a variety of services including short courses for practicing health care professionals, training for caregivers, and information lines for professionals and patients and families to contact.

A More Coordinated Approach to Training Health Professionals, Developing and Disseminating "Best Practice" Information, and Providing Support to Patients and Families Could Improve the Availability and Provision of Palliative Care

The experience and expertise that is being developed by innovative palliative care programs both within and outside of Virginia can be used in establishing a coordinated system of care. As previously stated, Virginia has taken steps to address a number of issues regarding palliative care. However, there is no state-level organization or entity that provides overall coordination of the state's efforts to ensure that: (i) health professionals have access to current information on palliative care and have resource centers to learn about "best practices" when treating patients; (ii) patients and their families receive useful information and other support; and (iii) information regarding the various palliative care programs throughout the Commonwealth is available to both providers and patients. A state-level palliative care entity could function as an important resource for both providers and patients. Such an entity also could facilitate information-sharing among the various palliative care programs across the state, and function as a coordinating body for activities requiring participation by all the palliative care programs such as submitting proposals for grant funding and conducting research.

IV.
Policy Options

The following Policy Options are offered for consideration by the Joint Commission on Health Care. They do not represent the entire range of actions that the Joint Commission may wish to pursue with regard to the provision of palliative care in Virginia.

Option I: **Take No Action**

Option II: **Include in the 2001 workplan for the Joint Commission on Health Care, further study and analysis of health insurance coverage (including Medicaid coverage) for palliative care. The study would address: (i) eligibility criteria/medical necessity determinations, (ii) covered and non-covered services, (iii) reimbursement policies, and (iv) other issues as appropriate. In conducting the study, JCHC staff could form a task force of insurance representatives, state agency representatives, palliative care providers, and advocacy groups.**

Option III: **Introduce a budget amendment (language and funding) directing the Commonwealth's three academic health centers to develop collaboratively a plan for establishing a Virginia Palliative Care Institute which would: (i) serve as the Commonwealth's organizational entity responsible for addressing palliative care issues, coordinating palliative care functions, and seeking grant funding; (ii) develop one or more resource centers to conduct or coordinate training programs and to act as information sources for health care professionals, and to provide outreach and information for patients and families regarding palliative care; and (iii) conduct ongoing research on "best practices" and other palliative care issues. The plan would address the functions and management of the Institute, as well as the staffing and funding necessary to support the Institute's operations. In developing the plan, the academic health centers shall involve other appropriate state agencies, palliative care providers, health care professionals, and advocacy groups. The plan would be submitted to the Governor, the 2002**

Session of the General Assembly, and the Joint Commission on Health Care.

Option IV: Introduce a budget amendment (language) directing the academic health centers to require specific core curriculum coursework on palliative care and end-of-life issues for their medical, nursing, and pharmacy schools. The budget language would include a requirement that the academic health centers report back to the Governor, the 2002 Session of the General Assembly, and the Joint Commission on Health Care.

Option V: Introduce legislation directing the Virginia Department of Health Professions to promulgate regulations for the continued competence of licensed physicians, nurses, and pharmacists that specifically address knowledge related to palliative care. [*This option would establish continued competence requirements for the Board of Nursing and would modify existing requirements for the Boards of Medicine and Pharmacy.*]

Option VI: Introduce legislation to provide statutory authority for the Virginia Department of Health to license both residential and inpatient hospice beds with the objective of alleviating the need to be licensed as assisted living facilities, nursing facilities, or hospitals.

APPENDIX A

COMMONWEALTH OF VIRGINIA
HOUSE OF DELEGATES
RICHMOND

VANCE WILKINS, JR.
SPEAKER

SPEAKER'S ROOM
STATE CAPITOL
POST OFFICE BOX 406
RICHMOND, VIRGINIA 23218

TWENTY-FOURTH DISTRICT

COMMITTEE ASSIGNMENTS
RULES (CHAIRMAN)

March 10, 2000

Mr. Patrick W. Finnerty
Executive Director, Joint Commission on Health Care
Old City Hall, Suite 115
1001 East Broad Street
Richmond, Virginia 23219

Dear Mr. Finnerty:

During the 2000 Session of the General Assembly, the House Committee on Rules considered House Joint Resolution 369, patroned by Del. Harvey B. Morgan, which directed the Joint Commission on Health Care, in conjunction with several professional health care associations, to study issues involved in palliative care. In an effort to reduce the number of study resolutions, House Joint Resolution 369 was among those that were not reported. However, the House Rules Committee believes that the issues addressed by the resolution merit review. Therefore, the Commission is directed to undertake the study and to submit a written report of its findings and any recommendations to the Governor and to the 2001 Session of the General Assembly. It is requested that you notify Del. Morgan of any meetings that are scheduled by the Commission to consider the study issues, and that you regularly apprise the patron concerning the Commission's deliberations on such matters. Further, please note that this study request expires at the end of the 2000 legislative year. I am enclosing a copy of HJR 369 for informational purposes so that you may be informed of the objectives of the study.

Your cooperation and assistance in this matter are appreciated.

Sincerely,

S. Vance Wilkins, Jr.
Speaker

/bhe
Enclosure (HJR 369)
cc: The Honorable Harvey B. Morgan
The Honorable Bruce F. Jamerson
The Honorable Susan Clarke Schaar

003948856

HOUSE JOINT RESOLUTION NO. 369

Offered January 25, 2000

Requesting the Joint Commission on Health Care, in conjunction with the American Cancer Society, Hospice, the Medical Society of Virginia, the Virginia Nurses Association, the Virginia Pharmacists Association, the Hospital and Health Care Association, and the Virginia Cancer Pain Initiative, to study the issues involved in palliative care.

Patrons—Morgan, Baskerville and Darner; Senators: Couric, Howell and Mims

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Consent to introduce

Referred to Committee on Rules

WHEREAS, data indicate that 50 to 90 percent of patients with end-of-life diseases die with pain and other symptoms; and,

WHEREAS, it is increasingly recognized that pain exists along with other symptoms in end-of-life diseases; and,

WHEREAS, palliative care is an interdisciplinary therapeutic model that focuses on the comprehensive management of the physical, psychological, social, and spiritual needs of patients and their families with progressive incurable illnesses; and

WHEREAS, palliative care should be integrated into routine care across all health care disciplines; and

WHEREAS, pain management has been addressed in the past through various General Assembly studies dating back to 1994; however, the concept of palliative care has not been explored; and,

WHEREAS, in Virginia, there is no central location for patients and families to receive comprehensive information regarding palliative care; and

WHEREAS, a comprehensive plan for education and training of health care providers does not currently exist in Virginia; and

WHEREAS, legal, organizational, and economic obstacles may further hamper quality of care at the end of life; and,

WHEREAS, palliative care includes a broad range of interventions that together offer the patient and family the best possible quality of life throughout the course of the disease; now, therefore, be it

RESOLVED, by the House of Delegates, the Senate concurring, That the Joint Commission on Health Care, in conjunction with the American Cancer Society, Hospice, the Medical Society of Virginia, the Virginia Nurses Association, the Virginia Pharmacists Association, the Hospital and Health Care Association, and the Virginia Cancer Pain Initiative, study the issues involved in palliative care. In its deliberations, the Joint Commission shall address the following issues: (i) identify a central resource for patients and families; (ii) designate a central information source, as well as a training program for health professionals; (iii) identify barriers (access, economic, organizational, ethical, and legal barriers) as well as deficiencies that currently exist in the health care system; and, (iv) develop an evaluation plan to assess quality and outcomes of palliative care in order to ensure that the patient and his family are able to maintain the best possible quality of life throughout the course of the disease; and, be it

RESOLVED FURTHER, That a funding mechanism shall be created to accomplish the palliative care initiatives.

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 2001 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

Code of Virginia

§ 38.2-3418.11. Coverage for hospice care.

A. Notwithstanding the provisions of § 38.2-3419, each insurer proposing to issue individual or group accident and sickness insurance policies providing hospital, medical and surgical, or major medical coverage on an expense-incurred basis; each corporation providing individual or group accident and sickness subscription contracts; and each health maintenance organization providing a health care plan for health care services shall provide coverage for hospice services under such policy, contract or plan delivered, issued for delivery or renewed in this Commonwealth on and after July 1, 1999.

B. As used in this section:

"Hospice services" shall mean a coordinated program of home and inpatient care provided directly or under the direction of a hospice licensed under Article 7 (§ 32.1-162.1 et seq.) of Chapter 5 of Title 32.1, and shall include palliative and supportive physical, psychological, psychosocial and other health services to individuals with a terminal illness utilizing a medically directed interdisciplinary team.

"Individuals with a terminal illness" shall mean individuals whose condition has been diagnosed as terminal by a licensed physician, whose medical prognosis is death within six months, and who elect to receive palliative rather than curative care.

"Medicare" shall mean Title XVIII of the Social Security Act.

"Palliative care" shall mean treatment directed at controlling pain, relieving other symptoms, and focusing on the special needs of the patient as he experiences the stress of the dying process, rather than treatment aimed at investigation and intervention for the purpose of cure or prolongation of life.

C. For the purposes of this section, documentation requirements shall be no greater than those required for the same services under Medicare.

D. Nothing in this section shall prohibit an insurer, corporation, or health maintenance organization from offering or providing coverage for hospice services when it cannot be demonstrated that the illness is terminal or for individuals with life expectancies of longer than six months.

E. The provisions of this section shall not apply to short-term travel, accident only, short-term nonrenewable policies of not more than six months' duration, or to policies or contracts designed for issuance to persons eligible for coverage under Title XVIII of the Social Security Act, known as Medicare, or any other similar coverage under state or federal governmental plans.

APPENDIX C

JOINT COMMISSION ON HEALTH CARE

SUMMARY OF PUBLIC COMMENTS:
Palliative Care Study
HJR 369

Individuals/Organizations Submitting Comments

A total of 11 individuals and organizations submitted comments in response to the Palliative Care Report.

- Alzheimer's Association
- American Cancer Society
- Gregory J. Huber
- The Medical Society of Virginia
- Oncology and Hematology Associates of Southwest Virginia, Inc.
- Virginia Academy of Family Physicians
- Virginia Association of Health Plans
- Virginia Association for Hospices, Inc.
- Virginia Association of Nonprofit Homes for the Aging
- Virginia Health Care Association
- Virginia Hospital and Healthcare Association

Policy Options Included in the Palliative Care Issue Brief

Option I: **Take No Action**

Option II: **Include in the 2001 workplan for the Joint Commission on Health Care, further study and analysis of health insurance coverage (including Medicaid coverage) for palliative care. The study would address: (i) eligibility criteria/medical necessity**

determinations, (ii) covered and non-covered services, (iii) reimbursement policies, and (iv) other issues as appropriate. In conducting the study, JCHC staff could form a task force of insurance representatives, state agency representatives, palliative care providers, and advocacy groups.

Option III: Introduce a budget amendment (language and funding) directing the Commonwealth's three academic health centers to develop collaboratively a plan for establishing a Virginia Palliative Care Institute which would: (i) serve as the Commonwealth's organizational entity responsible for addressing palliative care issues, coordinating palliative care functions, and seeking grant funding; (ii) develop one or more resource centers to conduct or coordinate training programs and to act as information sources for health care professionals, and to provide outreach and information for patients and families regarding palliative care; and (iii) conduct ongoing research on "best practices" and other palliative care issues. The plan would address the functions and management of the Institute, as well as the staffing and funding necessary to support the Institute's operations. In developing the plan, the academic health centers shall involve other appropriate state agencies, palliative care providers, health care professionals, and advocacy groups. The plan would be submitted to the Governor, the 2002 Session of the General Assembly, and the Joint Commission on Health Care.

Option IV: Introduce a budget amendment (language) directing the academic health centers to

require specific core curriculum coursework on palliative care and end-of-life issues for their medical, nursing, and pharmacy schools. The budget language would include a requirement that the academic health centers report back to the Governor, the 2002 Session of the General Assembly, and the Joint Commission on Health Care.

Option V: **Introduce legislation directing the Virginia Department of Health Professions to promulgate regulations for the continued competence of licensed physicians, nurses, and pharmacists that specifically address knowledge related to palliative care. [*This option would establish continued competence requirements for the Board of Nursing and would modify existing requirements for the Boards of Medicine and Pharmacy.*]**

Option VI: **Introduce legislation to provide statutory authority for the Virginia Department of Health to license both residential and inpatient hospice beds with the objective of alleviating the need to be licensed as assisted living facilities, nursing facilities, or hospitals.**

Overall Summary of Comments

The following table summarizes the comments that were received on each Policy Option. As shown, Option II was supported by the largest number of commenters (eight) followed by seven favorable comments for Option III, six for Option IV, five for Option VI, and four for Option V. Option V was specifically opposed by three commenters, Option IV was opposed by two commenters, while Options II and VI each received one comment in opposition. No one commented in opposition to Option III.

Policy Option	Number of Comments in Support	Number of Comments in Opposition
I	0	10
II	8	1
III	7	0
IV	6	2
V	4	3
VI	5	1

Summary of Individual Comments

Alzheimer's Association

Ian Kremer, Esq. commented on behalf of the Alzheimer's Association in support of Options II through VI. Mr. Kremer indicated many of the obstacles to receiving palliative care, that are identified in the report, are obstacles faced by people with dementia. Mr. Kremer stated, "medical practitioners often cannot or will not forecast how long a dementia patient has left to live, which disqualifies the patient from hospice services. Many other medical practitioners either are unaware or insensitive to the capacity of people with dementia to experience physical sensation ranging from discomfort to extraordinary pain and therefore provide inadequate pain management care."

American Cancer Society

Patrick Coyne, a volunteer with the American Cancer Society and Ashby Watson, President of the Virginia Cancer Pain Initiative commented in support of Options III and VI. In commenting on Option III, the need to have a centrally located resource center "attached to an institution with structure and expertise in place that could provide information, outreach, training, etc." was supported. However, it was noted further that a "statewide consortium/institute coordinated out of the three academic medical centers...would likely be a more expensive, time, and labor intensive option...[but] would be more likely to obtain large grants that focus on palliative care." Option VI was considered to be helpful to a few agencies in Virginia but "it would not solve the larger issue of providing palliative care in poor inner city and rural areas of Virginia."

Mr. Coyne and Ms. Ashby indicated opposition to Options I and II. Option II was opposed because data on financial barriers presented by Medicare and Medicaid already exists such that "we believe this option has already been addressed."

Gregory J. Huber

Gregory J. Huber commented in support of Options II and III. Option III was seen as a "large step...because it recognizes the need for a statewide, organized effort to provide this much needed health service."

Mr. Huber indicated opposition to Options IV and V. Requiring caregivers to take courses on palliative care in order to receive a license was seen to be counterproductive to developing "a strong foundation in the basics." Mr. Huber supported instead, the idea of providing for courses in palliative care that could be taken on a voluntary basis through the Institute as detailed in Option III.

The Medical Society of Virginia

Michael Jurgensen, Director of Health Policy, expressed support for Option II indicating: "Further study of the more detailed issues dealing with reimbursement and medical necessity issues will be instructive." Mr. Jurgensen also indicated that Options III and VI should be considered in completing further study to determine whether those options should be supported.

Mr. Jurgensen commented in opposition to Options IV and V noting that individual medical centers and individual practitioners should determine educational needs.

Oncology and Hematology Associates of Southwest Virginia, Inc.

William A. Fintel, M.D. commented in support of Options II through VI. Dr. Fintel indicated "there is merit in all of the options two through six and would like to voice...support for what you have done and in the direction you are going."

Virginia Academy of Family Physicians

James Ghaphery, M.D., physician representative, commented in support of Option II. Dr. Ghaphery stated that the additional information provided by a study would mean that "a better decision can be made concerning what action the state should pursue in regard to Options 3, 4, and 6."

Dr. Ghaphery commented in opposition to Option V stating that it "may not be necessary at this time." Dr. Ghaphery indicated that courses and workshops on pain management are available from a variety of sources and that pain management guidelines have been adopted by The Medical Society of Virginia.

Virginia Association of Health Plans

Lynn M. Warren, RN, MPH, Director of Policy, did not specifically support or oppose any of the proposed options. Ms. Warren stated: "To date, there is limited information regarding coverage for palliative care, especially as it relates to services provided to individuals with chronic, rather than terminal, illnesses. As such, VAHP believes that some of the conclusions of the study relating to third-party payors, especially private sector insurers, may be premature or perhaps even inaccurate. For example, VAHP does not believe that there is sufficient evidence to support statements such as 'third-party reimbursement encourages the provision of therapeutic care rather than palliative services' and 'reimbursement for palliative care is relatively low.' Accordingly, we believe that any review of health insurance coverage for palliative care should not only examine the degree to which and how these services are currently being provided in the marketplace but revisit some of the assumptions made in the study."

Virginia Association for Hospices, Inc.

W. R. Watts, Executive Director, commented in support of Options II, III, IV, and VI. In commenting on Option II, Mr. Watts indicated that study is also needed on the Medicare policy of only covering the cost of skilled care within long-term care facilities. The majority of terminally ill individuals require intermediate rather than skilled care. Further, Mr. Watts noted: "Even when a terminally ill patient meets Medicaid eligibility criteria, the 6-month or less prognosis required by hospice may not allow enough time to complete the screening process to obtain Medicaid." In commenting on Option III, Mr. Watts supported the inclusion of "providers, regulators, and consumer groups in addition to academic institutions" within the Palliative Care Institute. "It is clear that limited initiatives by providers, government or academia have not been effective and major sources of grants for such programs, such as the Robert Wood Johnson Foundation, are reluctant to fund limited efforts."

Mr. Watts indicated support of the intent of Option V but noted that "since many aspects of palliative care are rapidly emerging, criteria for professional competency may not be readily available."

Virginia Association of Nonprofit Homes for the Aging

Marcia A. Melton, Vice President for Public Policy commented in support of Options III and IV.

Virginia Health Care Association

Mary Lynne Bailey, Vice President, Legal and Government Affairs, indicated support for Options II, IV, and V. Ms. Bailey also stated: "Although VHCA would not oppose Option III (a Virginia Palliative Care Institute), we believe establishment of a task force to address eligibility, services, reimbursement issues would be a valuable first step."

Ms. Bailey indicated opposition to Option VI noting that statutory authority to license hospice beds does not seem to be needed at this time.

Virginia Hospital and Healthcare Association

Susan C. Ward, Vice President and General Counsel, commented in support of Options II through IV. In commenting on Option II, Ms. Ward indicated: "proposing that the Joint Commission on Health Care further analyze health insurance and Medicaid coverage for palliative care, would help to clarify and evaluate a very complex set of reimbursement policies that have, in many of the ways discussed in the brief, discouraged the provision of palliative care." With regard to Option VI, Ms. Ward stated that VHHA would be supportive "but only to the extent that such a change would preserve the concept of hospice as a way of caring for very sick and dying patients, regardless of where that caring takes place...and not simply as a physical bed that triggers particular reimbursement and other practices."

JOINT COMMISSION ON HEALTH CARE

Executive Director

Patrick W. Finnerty

Senior Health Policy Analysts

Joseph J. Hilbert
E. Kim Snead

Office Manager

Mamie V. White

Joint Commission on Health Care
Old City Hall, Suite 115
1001 East Broad Street
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