

**THE ADVANCE CARE PLANNING AND COMPASSIONATE CARE ACT OF 2009**  
Section-by-Section Summary

**TITLE I – ADVANCE CARE PLANNING**

**CONSUMER EDUCATION: NATIONAL INITIATIVES**

**Sec. 101 Advance Care Planning Telephone Hotline.**

Requires the Secretary of HHS to establish a 24-hour toll-free telephone hotline in order to provide consumer information about what advance care planning is, why it is important, issues to be considered when advance care planning, how to establish advance directives, steps to ensure that a patient's wishes for end-of-life care are carried out, national and state-specific resources to help consumers and their families with advance care planning, and information on hospice and palliative care.

**Sec. 102. Advance Care Planning Information Clearinghouses.**

Not later than January 1, 2010, comprehensive advance care planning information would be added to the Department of Health and Human Services' National Clearinghouse for Long-Term Care website, including: content included in the national public education campaign, described below; content addressing what advance care planning is, why it is important, issues to be considered when advance care planning, how to establish advance directives, and steps to ensure that a patient's wishes for end-of-life care are carried out; national and state-specific resources to help consumers and their families with advance care planning, including, but not limited to, points of contact on end-of-life issues in state public health departments, state points of contact for legal service organizations (including those funded through the Older Americans Act), and state-specific advance directive forms; and information on hospice and palliative care, including their respective services and purposes.

*Pediatric Advance Care Planning Clearinghouse* – Not later than January 1, 2011, the Secretary, in consultation with the Administrator of Children and Families, shall develop a clearinghouse of information on pediatric advance care planning. This clearinghouse shall provide advance care planning information specific to children with life-threatening illnesses and their families. The Pediatric Advance Care Planning Clearinghouse shall be distinctly identifiable on the Administration for Children and Families website. HHS, in consultation with the Administrator of Children and Families, shall develop, maintain, and publicize the advance care planning information on this website on an ongoing basis.

**Sec. 103. Advance Care Planning Toolkit.**

The Secretary of HHS, in consultation with the Centers for Disease Control and Prevention, shall develop and update as necessary a consumer advance care planning toolkit, to be accessible and downloadable from the following HHS websites, no later than July 1, 2010: the Centers for Disease Control website, National Clearinghouse for

Long-Term Care website, and the Administration for Children and Families website. This toolkit shall at least be available in English and Spanish. It shall also be mentioned as a resource in the *Medicare and You* handbook.

**Sec. 104. National Public Education Campaign.**

The Department of Health and Human Services has a date certain – no later than July 1, 2010 – to implement the public education campaign required under the Patient Self-Determination Act of 1990 (P.L.101-508). However, P.L. 101-58 is amended to require that the public education campaign be conducted by the Centers for Disease Control and Prevention and that the content of the campaign be amended to inform the public of the importance of advance care planning and of a patient's right to participate and direct health care decisions.

**Sec. 105. Update of Medicare and Social Security Handbooks.**

The Secretary of HHS is required to update the “Planning Ahead” section of the *Medicare and You* handbook online immediately and in paper form at the next regular update after enactment of this legislation, to include an explanation of advance care planning and advance directives and a list of national and state-specific resources to help consumers and their families with advance care planning (including those created in this legislation). The Commissioner will update the Social Security Handbook online immediately and in paper form at the next regular update after enactment of this legislation, to include the same information.

**Sec. 106. Authorization of appropriations.**

To carry out Sections 101, 102, 103, 104 and 105, \$200,000,000 would be authorized to be appropriated over five years – \$195,000,000 over five years to the Secretary of HHS and \$5,000,000 over five years to the Commissioner of Social Security.

**CONSUMER EDUCATION: STATE AND LOCAL INITIATIVES**

**Sec. 111. Financial assistance for advance care planning.**

*Legal Services Grants for Advance Care Planning* – Beginning July 1, 2010, under the Legal Services Corporation Act, \$10,000,000 would be authorized to be appropriated in competitive grants per year for each fiscal year 2010 through 2014 for the purpose of providing advance care planning legal services to low-income individuals, their health care proxies and their families, including information about state-specific advance directives.

*SHIP Grants for Advance Care Planning* – Beginning July 1, 2010, \$12,000,000 per year for five years would be authorized to be appropriated to the CMS Program Management Account for the purpose of making grants to states for SHIPs, to be used to provide

advance care planning services to Medicare beneficiaries, their health care proxies and their families, including information about state-specific advance directives and ways to discuss individual care wishes with health care providers. Two-thirds of the total will be allocated among states that have adopted the 1993 *Uniform Health-Care Decisions Act*. One-third will be allocated among the states that have adopted Orders for Life-Sustaining Treatments (OLSTs) or similar advance care planning approaches. States that have adopted both will be eligible for both pots of funding.

*Medicaid Transformation Grants for Advance Care Planning* – Beginning July 1, 2010, \$20,000,000 per year for five years would be authorized to be appropriated in Medicaid Transformation grants to provide advance care planning information to Medicaid beneficiaries directly through Medicaid (e.g. by adding to enrollment information, provider offices, case management services, etc).

*Advance Care Planning Community Training Grants* – Beginning July 1, 2010, \$12,000,000 per year over five years would be authorized to be appropriated for the purpose of making competitive advance care planning grants available to state area agencies on aging.

## **PROVIDER EDUCATION**

### **Sec. 121. Public provider advance care planning website.**

No later than January 1, 2010, the Secretary, acting through the Administrator of the Centers of Medicare and Medicaid Services and the Director of the Agency for Healthcare Research and Quality, shall establish and continuously update a permanent website devoted to educating Medicare, Medicaid, IHS, CHIP and public health providers on each person's right to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment, and the existence of advance directives.

### **Sec. 122. Continuing education for physicians and nurses.**

The Secretary of Health and Human Services (HHS), acting through the Director of Health Resources and Services Administration, shall develop, in consultation with providers and state boards of medicine and nursing, continuing education requirements for current physicians and nurses on advance care planning and end-of-life care.

## **ORDERS FOR LIFE-SUSTAINING TREATMENTS (OLSTS)**

### **Sec. 131. Medicare coverage of consultation regarding orders for life sustaining treatment.**

This section would provide Medicare coverage for consultations regarding orders for life sustaining treatment (OLST). Orders for life sustaining treatment help seriously ill patients identify their treatment preferences using a clear, standardized template. Written

as actionable medical orders and signed by a physician, these forms help communicate patient preferences regarding intensity of medical intervention, transfers to the hospital, use of antibiotics, artificially administered nutrition, and resuscitation. The following states have implemented or are developing orders for life sustaining treatment programs at the local or statewide level: Alaska, California, Colorado, Florida, Georgia, Hawaii, Idaho, Iowa, Kansas, Louisiana, Maine, Michigan, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New York, North Carolina, North Dakota, Ohio, Oregon, Pennsylvania, Tennessee, Texas, Utah, Washington, West Virginia, Wisconsin and Wyoming.

**Sec. 132. Grants for programs for orders regarding life sustaining treatment.**

This section authorizes the appropriation of such sums as necessary for the Secretary of HHS to make grants available to eligible entities to establish new OLST programs; expand or enhance existing OLST programs; or provide a clearinghouse of information on, and consultative services for development and enhancement of, such programs.

**PORTABILITY OF ADVANCE DIRECTIVES AND HEALTH INFORMATION TECHNOLOGY**

**Sec. 141. Portability of advance directives.**

An advance directive validly executed outside of the state in which such advance directive is presented by an adult individual to a provider or organization shall be given the same effect by that provider or organization as an advance directive validly executed under the law of the state in which it is presented would be given effect.

**Sec. 142. State advance directive registries; Driver's license advance directive notation.**

*State Advance Directive Registries* – Beginning July 1, 2010, there is authorized to be appropriated \$20,000,000 to the Centers for Disease Control and Prevention to award competitive grants to state departments of health to establish and operate state advance directive registries. An advance directive registry is a secure, electronic database that is available free of charge to state residents, stores advance directive documents and makes such documents accessible to medical service providers in accordance with state and federal privacy laws. In order to receive funding under this section, each state must prepare an approved work plan. Additionally, for each year of funding, each state must submit a standard annual report to the CDC on the use of the funds, including the number of state residents served. A state can receive funding under this section without having a mechanism for state residents to note the existence of an advance directive on their drivers' licenses. At least seven states – Hawaii, Illinois, Louisiana, Minnesota, Montana, South Dakota, and Vermont – currently provide for driver's license notice of advance directives.

*Driver's License Advance Directive Notation* – Beginning July 1, 2010, there is authorized to be appropriated \$50,000,000 to the Centers for Disease Control and Prevention to award competitive grants to states to establish and operate a mechanism for state residents to note the existence of an advance directive on their drivers' licenses. In order to receive funding under this section, each state must prepare an approved work plan that includes a description of how the state will 1) disseminate information about advance directives at the time of driver's license application or renewal; 2) enable drivers to include a notice of having a directive on their licenses in a manner consistent with the way drivers may indicate their intent to be an organ donor on their license; 3) coordinate with the state department of health to ensure that the driver's advance directive is included in the state registry. Additionally, for each year of funding, each state must submit a standard annual report to the CDC on the use of the funds, including the number of state residents served. A state cannot receive funding under this section without having a state advance directive registry.

**Sec. 143. GAO Study and Report on Establishment of National Advance Directive Registry.**

Not later than 18 months after the date of enactment of this legislation, the Comptroller General shall study and report on the feasibility of a national registry for advance directives, taking into consideration the privacy provisions enacted under the Health Insurance Portability and Accountability Act of 1996.

**NATIONAL UNIFORM POLICY ON ADVANCE CARE PLANNING**

**Sec. 151. Study and report by the Secretary of regarding the establishment and implementation of a national uniform policy on advance directives.**

The Secretary of HHS would be required to conduct a comprehensive study on the establishment and implementation of a national uniform policy on advance directives for beneficiaries under Medicare and Medicaid. Not later than 18 months after enactment of this legislation, the Secretary of HHS shall, in consultation with the Uniform Law Commissioners and other interested parties, submit a report to Congress on this study, along with any recommendations.

**TITLE II – COMPASSIONATE CARE**

**WORKFORCE DEVELOPMENT**

**Sec. 201. National Geriatric and Palliative Care Services Corps.**

The Secretary of HHS, acting through the Director of the HRSA, and out of funds authorized to be appropriated to the Secretary under this section, shall create a National Geriatric and Palliative Care Service Corps, modeled after the National Health Service Corps, to be effective no later than January 1, 2012. This program will include loan-

forgiveness, scholarships, and direct financial incentives for physicians, nurses, and other professionals (as identified by the Secretary) to become geriatric or palliative care specialists. The Secretary shall report to Congress, at least six months prior to beginning date, the program's organization and application process, necessary funding, and targeted numbers by profession and by specialization (i.e., geriatric or palliative care).

**Sec. 202. Exemption of palliative medicine fellowship training from Medicare graduate medical education caps.**

Palliative medicine fellowship training programs approved by the Accreditation Council for Graduate Medical Education (ACGME) shall be exempt from the Medicare graduate medical education caps, effective no later than January 1, 2010.

**Sec. 203. Medical school curricula.**

The Secretary of HHS, in consultation with the Association of American Medical Colleges, shall determine and require of medical schools receiving federal funds, a minimum amount end-of-life training. Minimum amount of required training and training content shall be defined and disseminated to medical schools no later than July 1, 2011. Federally-funded medical schools will be required to meet these minimum requirements beginning no later than January 1, 2012.

**MEDICARE, MEDICAID, AND CHIP COVERAGE OF ADVANCE CARE PLANNING AND OTHER PALLIATIVE CARE**

**Sec. 211. Medicare and Medicaid coverage of consultation regarding advance care planning.**

*Medicare Advance Care Planning Consultation* – No later than January 1, 2011, in addition to the “Welcome to Medicare” physician consultation (enacted as part of MIPPA, P.L. 108-173), Medicare would be required to cover one advance care planning consultation for each Medicare recipient at least as frequently as every five years. However, for patients experiencing a qualifying health event, Medicare must cover such advance care planning consultations at the time of such qualifying event. Qualifying health events include: life-threatening or terminal diagnosis; chronic disease diagnosis; or admission to a long-term care facility, a skilled nursing facility, or hospice.

*Medicaid and CHIP Advance Care Planning Consultations* – Beginning January 1, 2011, Medicaid and CHIP would be required to cover one advance care planning consultation to each Medicaid recipient at least as frequently as every five years. However, for patients experiencing a qualifying health event (defined below), Medicaid and CHIP must cover such advance care planning consultations at the time of such qualifying event. Qualifying health events include: life-threatening or terminal diagnosis; chronic disease diagnosis; or admission to a long-term care facility, a skilled nursing facility, or hospice.

## **MEDICARE, MEDICAID, AND CHIP COVERAGE OF HOSPICE**

### **Sec. 221. Adoption of MedPAC hospice payment methodology recommendations.**

The Secretary of HHS shall adopt the Medicare Payment Advisory Commission's 2008 hospice payment methodology reform recommendations to be effective January 1, 2013, with a brief transitional period as determined by the Secretary.

### **Sec. 222. Removing hospice inpatient days in setting per diem rates for critical access hospitals.**

The Secretary of HHS is required to remove Medicare-certified hospice inpatient days from the calculation Critical Access Hospital (CAH) per diem rates, effective January 1, 2011.

### **Sec. 223. Hospice payments for dual eligible individuals residing in nursing homes.**

Effective January 1, 2011, the Secretary, acting through the Administrator of CMS, is required to change nursing home payment for dual eligible hospice beneficiaries in nursing facilities so that Medicaid payments for room and board will be made directly to nursing facilities rather than to hospices.

### **Sec. 224. Delineation of respective care responsibilities of hospice programs and nursing homes.**

The Secretary, acting through the Administrator of CMS, shall delineate and enforce the respective care responsibilities of hospices and nursing homes for hospice beneficiaries in nursing homes, effective July 1, 2011.

### **Sec. 225. Medicare hospice program eligibility certification and recertification.**

The Secretary, in consultation with the Administrator of CMS, shall implement the following changes, to be effective on January 1, 2011: 1) A hospice physician or advanced practice nurse will visit the hospice patient to determine continued eligibility prior to the 180th day recertification and each subsequent recertification, and attest that such visits took place; and 2) Certifications and recertifications for eligibility will include a brief narrative describing the clinical basis for the patient's prognosis.

### **Sec. 226. Concurrent care for children.**

Effective January 1, 2011, Medicare, Medicaid and CHIP are required to provide concurrent coverage for both hospice and curative treatment for children 18 years of age and younger.

**Sec. 227. Making hospice a required benefit under Medicaid and CHIP.**

Effective January 1, 2011, hospice shall be a required benefit under Medicaid and CHIP. Currently, 48 states provide coverage for hospice under Medicaid.

**Sec. 228. Medicare hospice payment model demonstration projects.**

The Secretary, acting through the Director of the Agency for Healthcare Research and Quality and the Administrator of CMS, shall implement demonstration projects, beginning no later than July 1, 2012, that examine ways to improve how the Medicare hospice benefit predicts disease trajectory. Projects shall include (but are not limited to) models that: better and more appropriately care for, and transition as needed, “pre-hospice” patients; and better and more appropriately care for long-term patients who are not recertified in hospice but still need palliative care.

**Sec. 229. MedPAC studies and reports.**

*MedPAC Study and Report Regarding an Alternative Payment Methodology for Hospice Care Under the Medicare Program* – Not later than June 15, 2013, MedPAC is required to study and report on a hospice prospective reimbursement methodology based on diagnoses.

*MedPAC Study and Report Regarding Rural Hospice Transportation Costs Under the Medicare Program* – Not later than June 15, 2013, MedPAC is required to evaluate and report on rural Medicare hospice transportation mileage to determine potential Medicare reimbursement changes to account for potential higher costs.

*MedPAC Evaluation of Reimbursement Disincentives to Elect Medicare Hospice Within the Medicare Skilled Nursing Benefit* – Not later than June 15, 2013, MedPAC is required to evaluate and make recommendations on how to remove Medicare reimbursement disincentives for patients in a skilled nursing facility who want to elect hospice.

**Sec. 230. HHS Evaluations.**

*Evaluation of Access to Hospice and Hospital-Based Palliative Care* – Not later than December 31, 2012, the Secretary of HHS, acting through the Administrator of HRSA, shall evaluate and make recommendations regarding geographic areas and populations underserved by hospice and hospital-based palliative care.

*Evaluation of Awareness and Use of Respite Care by Hospice Providers Under Medicare and Medicaid* – Not later than December 31, 2011, the Secretary of HHS, acting through the Administrator of CMS, shall evaluate and make recommendations regarding the awareness and use of the respite benefit by informal caregivers serving Medicare and Medicaid beneficiaries.

## **QUALITY IMPROVEMENT: DEVELOPMENT OF CORE END-OF-LIFE CARE QUALITY MEASURES**

### **Sec. 241. Patient Satisfaction Surveys.**

No later than January 1, 2012, the Secretary of HHS, acting through the Administrator of CMS, shall establish a mechanism for patients in relevant provider settings to provide feedback to CMS regarding their care at the end of life. This information shall be incorporated into current mechanisms for delivering quality of care information to consumers through CMS, including the Hospital Compare and Nursing Home Compare.

### **Sec. 242. Development of core end-of-life care quality measures across each relevant provider setting.**

The Secretary of HHS, acting through the Director of the Agency for Healthcare Research and Quality, shall require specific end-of-life care quality measures for each relevant provider setting, as identified by the Director, to be reported starting no later than April 1, 2011. The Secretary shall disseminate these requirements for all affected providers no later than April 1, 2012. Measures may be structure-oriented (e.g., presence of a hospital-based palliative care program), process-oriented (e.g., whether patients were asked if they had an advance directive), and/or outcome-oriented (e.g., family satisfaction with care). Reporting requirements will be consistent with current laws and regulations, and take into account existing measures, needs of patient population, and services provided.

### **Sec. 243. Certification of Hospital-Based Palliative Care Programs.**

The Secretary of HHS, Acting through the Director of AHRQ, will identify and direct an appropriate public and/or private entity to develop standards and processes for certification of hospital-based palliative care programs. The Secretary will report to Congress, no later than January 1, 2012, the standards and processes for such accreditation, and make final standards and processes effective through the certifying entity, no later than July 1, 2012.

### **Sec. 244. Survey and data requirements for all federally participating hospice programs.**

*Hospice Resource Inputs Data* – Consistent with the MedPAC recommendations from March 2008, hospices shall, beginning January 1, 2011, report data to the Secretary of Health and Human Services that reflects: visit type (admission, routine, emergency, education for family, other); visit length; professional or paraprofessional disciplines involved in visit (including nurse, social worker, home health aide, physician, nurse practitioner, chaplain/spiritual counselor, counselor, dietician, physical therapist, occupational therapist, speech language pathologist, music or art therapist), including for bereavement and support services provided to a patient's family after a patient's death; drugs and other therapeutic interventions used to treat the patient; and medical equipment and supplies used by the patient.

*Hospice Surveys* – The Secretary, acting through the Director of the Centers for Medicare and Medicaid Services, shall establish, effective July 1, 2010, that: 1) a hospice program seeking certification will be subject to an initial survey by an appropriate state or local agency, or an approved accreditation agency, within six months of beginning operations; and 2) standard surveys for all certified hospices will occur not later than 36 months after the date of the previous survey for the given hospice.

## **ADDITIONAL REPORTS, RESEARCH, AND EVALUATIONS**

### **Sec. 251. National Center on Palliative and End-of-Life Care.**

The Director of the NIH shall establish a National Center on Palliative and End-of-Life Care within the NIH, to be operational no later than July 1, 2011, with ongoing funding, authority, and organizational resources commensurate with a Center of the NIH. Initial funding levels shall take into account that this has been an underfunded area of research. The Director of the Center will report directly to the Director of the NIH. This Center shall be responsible for 1) developing and continuously updating a research agenda with the goals of a) better biomedical understanding of the end of life; and b) improvement in the quality of care and life at the end of life; and 2) funding peer-review-selected extra- and intra-mural research that includes evaluation of existing, and the development of new, palliative and end-of-life care interventions and approaches.

### **Sec. 252. National Mortality Followback Survey.**

The Secretary of HHS, acting through the Director of the CDC, shall re-establish the National Mortality Followback Survey to be conducted on an ongoing basis beginning no later than December 31, 2010, with the goal of better understanding of current end-of-life care in the nation. Additional questions will be determined and added as necessary on an ongoing basis with input from relevant research entities, including the Agency for Healthcare Research and Quality. At a minimum, these questions will address whether the respondent's loved one:

- had an advance directive, and if so, when it was completed;
- had a durable power of attorney, and if so, when it was completed;
- had discussed his or her wishes with loved ones, and if so, when;
- had discussed his or her wishes with his or her physician, and if so, when;
- was, in the opinion of the respondent, satisfied with the care he or she received in the last year of life and in the last week of life;
- was cared for by hospice, and if so, when;
- was cared for by palliative care specialists, and if so, when;
- whether the patient received effective pain management (if needed).

The respondent will also be asked about the experience of the main caregiver (including the respondent), and whether he or she received sufficient support in this role.

**Sec. 253. Demonstration Projects for Use of Telemedicine Services in Advance Care Planning.**

The Secretary will direct multi-year demonstration projects, beginning no later than July 1, 2011, in which physicians or advance practice nurses of hospital-based palliative care programs provide advance care planning consultations via televideo to geographically distant patients and physicians. Funding is authorized to be appropriated as necessary for equipment and connection costs.

**Sec. 254. Inspector General Investigation of Fraud and Abuse.**

As recommended by MedPAC, not later than January 1, 2012, the Secretary of HHS shall direct the Office of the Inspector General to investigate the prevalence of financial relationships between hospices and long-term care facilities such as nursing facilities and assisted living facilities that may represent a conflict of interest and influence admissions to hospice; differences in patterns of nursing home referrals to hospice; the appropriateness of enrollment practices for hospices with unusual utilization patterns (e.g. high frequency of very long stays, very short stays, or enrollment of patients discharged from other hospices); and the appropriateness of hospice marketing materials and other admissions practices and potential correlations between length of stay and deficiencies in marketing or admissions practices.

**Sec. 255. GAO study and report on provider adherence to advance directives.**

Not later than January 1, 2012, the Comptroller General of the United States shall conduct a study of and issue a report on the extent to which providers are complying with the requirements of the Patient Self-Determination Act of 1990 as well as the requirements enacted under this new law regarding advance directives, together with such recommendations for administrative or legislative changes the Comptroller General determines appropriate.