

109TH CONGRESS
1ST SESSION

H. R. 2058

To amend titles XVIII and XIX of the Social Security Act and title III of the Public Health Service Act to improve access to information about individuals' health care options and legal rights for care near the end of life, to promote advance care planning and decisionmaking so that individuals' wishes are known should they become unable to speak for themselves, to engage health care providers in disseminating information about and assisting in the preparation of advance directives, which include living wills and durable powers of attorney for health care, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MAY 3, 2005

Mr. LEVIN (for himself, Mr. ABERCROMBIE, Mr. CARDIN, Mr. CASE, Mr. CASTLE, Mr. CLEAVER, Mr. CUMMINGS, Ms. DELAURO, Mr. ENGEL, Mr. FARR, Mr. HOLDEN, Mr. KILDEE, Mr. KIND, Mr. KUCINICH, Mr. LEWIS of Georgia, Mrs. MALONEY, Mrs. MCCARTHY, Mr. McDERMOTT, Mr. McNULTY, Mr. MEEK of Florida, Mr. GEORGE MILLER of California, Mr. MOORE of Kansas, Mr. ROSS, Ms. SLAUGHTER, Mr. SNYDER, Mr. UDALL of Colorado, Ms. WASSERMAN SCHULTZ, Mr. WAXMAN, Mr. DAVIS of Illinois, and Mr. OWENS) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To amend titles XVIII and XIX of the Social Security Act and title III of the Public Health Service Act to improve access to information about individuals' health care options and legal rights for care near the end of life, to promote advance care planning and decisionmaking

so that individuals' wishes are known should they become unable to speak for themselves, to engage health care providers in disseminating information about and assisting in the preparation of advance directives, which include living wills and durable powers of attorney for health care, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
 2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the
 5 “Advance Directives Improvement and Education Act of
 6 2005”.

7 (b) TABLE OF CONTENTS.—The table of contents of
 8 this Act is as follows:

- Sec. 1. Short title; table of contents.
- Sec. 2. Findings and purposes.
- Sec. 3. Medicare coverage of end-of-life planning consultations.
- Sec. 4. Improvement of policies related to the use and portability of advance directives.
- Sec. 5. Increasing awareness of the importance of end-of-life planning.
- Sec. 6. GAO studies and reports on end-of-life planning issues.

9 **SEC. 2. FINDINGS AND PURPOSES.**

10 (a) FINDINGS.—Congress makes the following find-
 11 ings:

12 (1) Every year 2,500,000 people die in the
 13 United States. Eighty percent of those people die in
 14 institutions such as hospitals, nursing homes, and
 15 other facilities. Chronic illnesses, such as cancer and
 16 heart disease, account for 2 out of every 3 deaths.

1 (2) In January 2004, a study published in the
2 Journal of the American Medical Association con-
3 cluded that many people dying in institutions have
4 unmet medical, psychological, and spiritual needs.
5 Moreover, family members of decedents who received
6 care at home with hospice services were more likely
7 to report a favorable dying experience.

8 (3) In 1997, the Supreme Court of the United
9 States, in its decisions in *Washington v. Glucksberg*
10 and *Vacco v. Quill*, reaffirmed the constitutional
11 right of competent adults to refuse unwanted med-
12 ical treatment. In those cases, the Court stressed the
13 use of advance directives as a means of safeguarding
14 that right should those adults become incapable of
15 deciding for themselves.

16 (4) A study published in 2002 estimated that
17 the overall prevalence of advance directives is be-
18 tween 15 and 20 percent of the general population,
19 despite the passage of the Patient Self-Determina-
20 tion Act in 1990, which requires that health care
21 providers tell patients about advance directives.

22 (5) Competent adults should complete advance
23 care plans stipulating their health care decisions in
24 the event that they become unable to speak for
25 themselves. Through the execution of advance direc-

1 tives, including living wills and durable powers of at-
 2 torney for health care according to the laws of the
 3 State in which they reside, individuals can protect
 4 their right to express their wishes and have them re-
 5 spected.

6 (b) PURPOSES.—The purposes of this Act are to im-
 7 prove access to information about individuals’ health care
 8 options and legal rights for care near the end of life, to
 9 promote advance care planning and decisionmaking so
 10 that individuals’ wishes are known should they become un-
 11 able to speak for themselves, to engage health care pro-
 12 viders in disseminating information about and assisting in
 13 the preparation of advance directives, which include living
 14 wills and durable powers of attorney for health care, and
 15 for other purposes.

16 **SEC. 3. MEDICARE COVERAGE OF END-OF-LIFE PLANNING**
 17 **CONSULTATIONS.**

18 (a) COVERAGE.—Section 1861(s)(2) of the Social Se-
 19 curity Act (42 U.S.C. 1395x(s)(2)), as amended by section
 20 642(a) of the Medicare Prescription Drug, Improvement,
 21 and Modernization Act of 2003 (Public Law 108–173; 117
 22 Stat. 2322), is amended—

23 (1) in subparagraph (Y), by striking “and” at
 24 the end;

1 (2) in subparagraph (Z), by inserting “and” at
2 the end; and

3 (3) by adding at the end the following new sub-
4 paragraph:

5 “(AA) end-of-life planning consultations (as de-
6 fined in subsection (bbb));”.

7 (b) SERVICES DESCRIBED.—Section 1861 of the So-
8 cial Security Act (42 U.S.C. 1395x), as amended by sec-
9 tion 706(b) of the Medicare Prescription Drug, Improve-
10 ment, and Modernization Act of 2003 (Public Law 108–
11 173; 117 Stat. 2339), is amended by adding at the end
12 the following new subsection:

13 “End-of-Life Planning Consultation

14 “(bbb) The term ‘end-of-life planning consultation’
15 means physicians’ services—

16 “(1) consisting of a consultation between the
17 physician and an individual regarding—

18 “(A) the importance of preparing advance
19 directives in case an injury or illness causes the
20 individual to be unable to make health care de-
21 cisions;

22 “(B) the situations in which an advance di-
23 rective is likely to be relied upon;

24 “(C) the reasons that the development of a
25 comprehensive end-of-life plan is beneficial and

1 the reasons that such a plan should be updated
 2 periodically as the health of the individual
 3 changes;

4 “(D) the identification of resources that an
 5 individual may use to determine the require-
 6 ments of the State in which such individual re-
 7 sides so that the treatment wishes of that indi-
 8 vidual will be carried out if the individual is un-
 9 able to communicate those wishes, including re-
 10 quirements regarding the designation of a sur-
 11 rogate decision maker (health care proxy); and

12 “(E) whether or not the physician is will-
 13 ing to follow the individual’s wishes as ex-
 14 pressed in an advance directive; and

15 “(2) that are furnished to an individual on an
 16 annual basis or immediately following any major
 17 change in an individual’s health condition that would
 18 warrant such a consultation (whichever comes
 19 first).”.

20 (c) WAIVER OF DEDUCTIBLE AND COINSURANCE.—

21 (1) DEDUCTIBLE.—The first sentence of sec-
 22 tion 1833(b) of the Social Security Act (42 U.S.C.
 23 1395l(b)) is amended—

24 (A) by striking “and” before “(6)”; and

1 (B) by inserting before the period at the
 2 end the following: “, and (7) such deductible
 3 shall not apply with respect to an end-of-life
 4 planning consultation (as defined in section
 5 1861(bbb))”.

6 (2) COINSURANCE.—Section 1833(a)(1) of the
 7 Social Security Act (42 U.S.C. 1395l(a)(1)) is
 8 amended—

9 (A) in clause (N), by inserting “(or 100
 10 percent in the case of an end-of-life planning
 11 consultation, as defined in section 1861(bbb))”
 12 after “80 percent”; and

13 (B) in clause (O), by inserting “(or 100
 14 percent in the case of an end-of-life planning
 15 consultation, as defined in section 1861(bbb))”
 16 after “80 percent”.

17 (d) PAYMENT FOR PHYSICIANS’ SERVICES.—Section
 18 1848(j)(3) of the Social Security Act (42 U.S.C. 1395w–
 19 4(j)(3)), as amended by section 611(c) of the Medicare
 20 Prescription Drug, Improvement, and Modernization Act
 21 of 2003 (Public Law 108–173; 117 Stat. 2304), is amend-
 22 ed by inserting “(2)(AA),” after “(2)(W),”.

23 (e) FREQUENCY LIMITATION.—Section 1862(a)(1) of
 24 the Social Security Act (42 U.S.C. 1395y(a)(1)), as
 25 amended by section 613(c) of the Medicare Prescription

1 Drug, Improvement, and Modernization Act of 2003 (Pub-
 2 lic Law 108–173; 117 Stat. 2306), is amended—

3 (1) by striking “and” at the end of subpara-
 4 graph (L);

5 (2) by striking the semicolon at the end of sub-
 6 paragraph (M) and inserting “, and”; and

7 (3) by adding at the end the following new sub-
 8 paragraph:

9 “(N) in the case of end-of-life planning con-
 10 sultations (as defined in section 1861(bbb)), which
 11 are performed more frequently than is covered under
 12 paragraph (2) of such section;”.

13 (f) EFFECTIVE DATE.—The amendments made by
 14 this section shall apply to services furnished on or after
 15 January 1, 2006.

16 **SEC. 4. IMPROVEMENT OF POLICIES RELATED TO THE USE**
 17 **AND PORTABILITY OF ADVANCE DIRECTIVES.**

18 (a) MEDICARE.—Section 1866(f) of the Social Secu-
 19 rity Act (42 U.S.C. 1395cc(f)) is amended—

20 (1) in paragraph (1)—

21 (A) in subparagraph (B), by inserting
 22 “and if presented by the individual (or on be-
 23 half of the individual), to include the content of
 24 such advance directive in a prominent part of
 25 such record” before the semicolon at the end;

1 (B) in subparagraph (D), by striking
2 “and” after the semicolon at the end;

3 (C) in subparagraph (E), by striking the
4 period at the end and inserting “; and”; and

5 (D) by inserting after subparagraph (E)
6 the following new subparagraph:

7 “(F) to provide each individual with the oppor-
8 tunity to discuss issues relating to the information
9 provided to that individual pursuant to subpara-
10 graph (A) with an appropriately trained profes-
11 sional.”;

12 (2) in paragraph (3), by striking “a written”
13 and inserting “an”; and

14 (3) by adding at the end the following new
15 paragraph:

16 “(5)(A) In addition to the requirements of paragraph
17 (1), a provider of services, Medicare Advantage organiza-
18 tion, or prepaid or eligible organization (as the case may
19 be) shall give effect to an advance directive executed out-
20 side the State in which such directive is presented, even
21 one that does not appear to meet the formalities of execu-
22 tion, form, or language required by the State in which it
23 is presented to the same extent as such provider or organi-
24 zation would give effect to an advance directive that meets
25 such requirements, except that a provider or organization

1 may decline to honor such a directive if the provider or
2 organization can reasonably demonstrate that it is not an
3 authentic expression of the individual’s wishes concerning
4 his or her health care. Nothing in this paragraph shall
5 be construed to authorize the administration of medical
6 treatment otherwise prohibited by the laws of the State
7 in which the directive is presented.

8 “(B) The provisions of this paragraph shall preempt
9 any State law to the extent such law is inconsistent with
10 such provisions. The provisions of this paragraph shall not
11 preempt any State law that provides for greater port-
12 ability, more deference to a patient’s wishes, or more lati-
13 tude in determining a patient’s wishes.”.

14 (b) MEDICAID.—Section 1902(w) of the Social Secu-
15 rity Act (42 U.S.C. 1396a(w)) is amended—

16 (1) in paragraph (1)—

17 (A) in subparagraph (B)—

18 (i) by striking “in the individual’s
19 medical record” and inserting “in a promi-
20 nent part of the individual’s current med-
21 ical record”; and

22 (ii) by inserting “and if presented by
23 the individual (or on behalf of the indi-
24 vidual), to include the content of such ad-

1 vance directive in a prominent part of such
2 record” before the semicolon at the end;

3 (B) in subparagraph (D), by striking
4 “and” after the semicolon at the end;

5 (C) in subparagraph (E), by striking the
6 period at the end and inserting “; and”; and

7 (D) by inserting after subparagraph (E)
8 the following new subparagraph:

9 “(F) to provide each individual with the oppor-
10 tunity to discuss issues relating to the information
11 provided to that individual pursuant to subpara-
12 graph (A) with an appropriately trained profes-
13 sional.”;

14 (2) in paragraph (4), by striking “a written”
15 and inserting “an”; and

16 (3) by adding at the end the following para-
17 graph:

18 “(6)(A) In addition to the requirements of paragraph
19 (1), a provider or organization (as the case may be) shall
20 give effect to an advance directive executed outside the
21 State in which such directive is presented, even one that
22 does not appear to meet the formalities of execution, form,
23 or language required by the State in which it is presented
24 to the same extent as such provider or organization would
25 give effect to an advance directive that meets such require-

1 ments, except that a provider or organization may decline
2 to honor such a directive if the provider or organization
3 can reasonably demonstrate that it is not an authentic ex-
4 pression of the individual's wishes concerning his or her
5 health care. Nothing in this paragraph shall be construed
6 to authorize the administration of medical treatment oth-
7 erwise prohibited by the laws of the State in which the
8 directive is presented.

9 “(B) The provisions of this paragraph shall preempt
10 any State law to the extent such law is inconsistent with
11 such provisions. The provisions of this paragraph shall not
12 preempt any State law that provides for greater port-
13 ability, more deference to a patient's wishes, or more lati-
14 tude in determining a patient's wishes.”.

15 (c) EFFECTIVE DATES.—

16 (1) IN GENERAL.—Subject to paragraph (2),
17 the amendments made by subsections (a) and (b)
18 shall apply to provider agreements and contracts en-
19 tered into, renewed, or extended under title XVIII of
20 the Social Security Act (42 U.S.C. 1395 et seq.),
21 and to State plans under title XIX of such Act (42
22 U.S.C. 1396 et seq.), on or after such date as the
23 Secretary of Health and Human Services specifies,
24 but in no case may such date be later than 1 year
25 after the date of enactment of this Act.

1 (2) EXTENSION OF EFFECTIVE DATE FOR
2 STATE LAW AMENDMENT.—In the case of a State
3 plan under title XIX of the Social Security Act (42
4 U.S.C. 1396 et seq.) which the Secretary of Health
5 and Human Services determines requires State legis-
6 lation in order for the plan to meet the additional
7 requirements imposed by the amendments made by
8 subsection (b), the State plan shall not be regarded
9 as failing to comply with the requirements of such
10 title solely on the basis of its failure to meet these
11 additional requirements before the first day of the
12 first calendar quarter beginning after the close of
13 the first regular session of the State legislature that
14 begins after the date of enactment of this Act. For
15 purposes of the previous sentence, in the case of a
16 State that has a 2-year legislative session, each year
17 of the session is considered to be a separate regular
18 session of the State legislature.

19 **SEC. 5. INCREASING AWARENESS OF THE IMPORTANCE OF**
20 **END-OF-LIFE PLANNING.**

21 Title III of the Public Health Service Act (42 U.S.C.
22 241 et seq.) is amended by adding at the end the following
23 new part:

1 **“PART R—PROGRAMS TO INCREASE AWARENESS**
2 **OF ADVANCE DIRECTIVE PLANNING ISSUES**
3 **“SEC. 399Z-1. ADVANCE DIRECTIVE EDUCATION CAM-**
4 **PAIGNS AND INFORMATION CLEARING-**
5 **HOUSES.**

6 “(a) ADVANCE DIRECTIVE EDUCATION CAMPAIGN.—
7 The Secretary shall, directly or through grants awarded
8 under subsection (c), conduct a national public education
9 campaign—

10 “(1) to raise public awareness of the impor-
11 tance of planning for care near the end of life;

12 “(2) to improve the public’s understanding of
13 the various situations in which individuals may find
14 themselves if they become unable to express their
15 health care wishes;

16 “(3) to explain the need for readily available
17 legal documents that express an individual’s wishes,
18 through advance directives (including living wills,
19 comfort care orders, and durable powers of attorney
20 for health care); and

21 “(4) to educate the public about the availability
22 of hospice care and palliative care.

23 “(b) INFORMATION CLEARINGHOUSE.—The Sec-
24 retary, directly or through grants awarded under sub-
25 section (c), shall provide for the establishment of a na-
26 tional, toll-free, information clearinghouse as well as clear-

1 inghouses that the public may access to find out about
 2 State-specific information regarding advance directive and
 3 end-of-life decisions.

4 “(c) GRANTS.—

5 “(1) IN GENERAL.—The Secretary shall use at
 6 least 60 percent of the funds appropriated under
 7 subsection (d) for the purpose of awarding grants to
 8 public or nonprofit private entities (including States
 9 or political subdivisions of a State), or a consortium
 10 of any of such entities, for the purpose of conducting
 11 education campaigns under subsection (a) and estab-
 12 lishing information clearinghouses under subsection
 13 (b).

14 “(2) PERIOD.—Any grant awarded under para-
 15 graph (1) shall be for a period of 3 years.

16 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
 17 are authorized to be appropriated to carry out this section
 18 \$25,000,000.”.

19 **SEC. 6. GAO STUDIES AND REPORTS ON END-OF-LIFE PLAN-**
 20 **NING ISSUES.**

21 (a) STUDY AND REPORT ON COMPLIANCE WITH AD-
 22 VANCE DIRECTIVES AND OTHER ADVANCE PLANNING
 23 DOCUMENTS.—

24 (1) STUDY.—The Comptroller General of the
 25 United States shall conduct a study on the effective-

1 ness of advance directives in making patients' wishes
2 known and honored by health care providers.

3 (2) REPORT.—Not later than the date that is
4 18 months after the date of enactment of this Act,
5 the Comptroller General of the United States shall
6 submit to Congress a report on the study conducted
7 under paragraph (1) together with recommendations
8 for such legislation and administrative action as the
9 Comptroller General of the United States determines
10 to be appropriate.

11 (b) STUDY AND REPORT ON IMPLEMENTATION OF
12 THE MEDICARE COVERAGE FOR END-OF-LIFE PLANNING
13 CONSULTATIONS.—

14 (1) STUDY.—The Comptroller General of the
15 United States shall conduct a study on the imple-
16 mentation of the amendments made by section 3 (re-
17 lating to medicare coverage of end-of-life planning
18 consultations).

19 (2) REPORT.—Not later than 2 years after the
20 date of enactment of this Act, the Comptroller Gen-
21 eral of the United States shall submit to Congress
22 a report on the study conducted under paragraph
23 (1) together with recommendations for such legisla-
24 tion and administrative action as the Comptroller

1 General of the United States determines to be ap-
2 propriate.

3 (c) STUDY AND REPORT ON ESTABLISHMENT OF NA-
4 TIONAL ADVANCE DIRECTIVE REGISTRY.—

5 (1) STUDY.—The Comptroller General of the
6 United States shall conduct a study on the feasi-
7 bility of a national registry for advance directives,
8 taking into consideration the constraints created by
9 the privacy provisions enacted as a result of the
10 Health Insurance Portability and Accountability Act.

11 (2) REPORT.—Not later than 18 months after
12 the date of enactment of this Act, the Comptroller
13 General of the United States shall submit to Con-
14 gress a report on the study conducted under para-
15 graph (1) together with recommendations for such
16 legislation and administrative action as the Comp-
17 troller General of the United States determines to be
18 appropriate.

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