

Calendar No. 49

109TH CONGRESS
1ST SESSION

S. 570

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 SENATE OF THE UNITED STATES

MARCH 9, 2005

Mr. NELSON of Florida introduced the following bill; which was read the first time

MARCH 10, 2005

Read the second time and placed on the calendar

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 Education Act of 2005”.

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

Sec. 1. Short title; table of contents.

Sec. 2. Findings and purposes.

Sec. 3. Improvement of policies related to the use and portability of advance directives.

Sec. 4. Increasing awareness of the importance of End-of-Life planning.

Sec. 5. GAO study and report on establishment of national advance directive registry.

Sec. 6. Advance directives at State department of motor vehicles.

8 **SEC. 2. FINDINGS AND PURPOSES.**

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

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

16 (2) In January 2004, a study published in the
 17 Journal of the American Medical Association con-
 18 cluded that many people dying in institutions have

1 unmet medical, psychological, and spiritual needs.
2 Moreover, family members of decedents who received
3 care at home with hospice services were more likely
4 to report a favorable dying experience.

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

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

19 (5) Competent adults should complete advance
20 care plans stipulating their health care decisions in
21 the event that they become unable to speak for
22 themselves. Through the execution of advance direc-
23 tives, including living wills and durable powers of at-
24 torney for health care according to the laws of the
25 State in which they reside, individuals can protect

1 their right to express their wishes and have them re-
2 spected.

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

13 **SEC. 3. IMPROVEMENT OF POLICIES RELATED TO THE USE**
14 **AND PORTABILITY OF ADVANCE DIRECTIVES.**

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

17 (1) in paragraph (1)—

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

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

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

3 (D) by inserting after subparagraph (E)
4 the following new subparagraph:

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

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

12 (3) by adding at the end the following new
13 paragraph:

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

1 authentic expression of the individual’s wishes concerning
2 his or her health care. Nothing in this paragraph shall
3 be construed to authorize the administration of medical
4 treatment otherwise prohibited by the laws of the State
5 in which the directive is presented.

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

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

14 (1) in paragraph (1)—

15 (A) in subparagraph (B)—

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

20 (ii) by inserting “and if presented by
21 the individual (or on behalf of the indi-
22 vidual), to include the content of such ad-
23 vance directive in a prominent part of such
24 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 (4), by striking “a written”
13 and inserting “an”; and

14 (3) by adding at the end the following para-
15 graph:

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

1 can reasonably demonstrate that it is not an authentic ex-
2 pression of the individual’s wishes concerning his or her
3 health care. Nothing in this paragraph shall be construed
4 to authorize the administration of medical treatment oth-
5 erwise prohibited by the laws of the State in which the
6 directive is presented.

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

13 (c) EFFECTIVE DATES.—

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

24 (2) EXTENSION OF EFFECTIVE DATE FOR
25 STATE LAW AMENDMENT.—In the case of a State

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

17 **SEC. 4. INCREASING AWARENESS OF THE IMPORTANCE OF**
18 **END-OF-LIFE PLANNING.**

19 Title III of the Public Health Service Act (42 U.S.C.
20 241 et seq.) is amended by adding at the end the following
21 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 “The Secretary shall provide for the establishment of
7 a national, toll-free, information clearinghouse as well as
8 clearinghouses that the public may access to find out
9 about State-specific information regarding advance direc-
10 tive and end-of-life decisions.”.

11 **SEC. 5. GAO STUDY AND REPORT ON ESTABLISHMENT OF**
12 **NATIONAL ADVANCE DIRECTIVE REGISTRY.**

13 (a) **STUDY.**—The Comptroller General of the United
14 States shall conduct a study on the feasibility of a national
15 registry for advance directives, taking into consideration
16 the constraints created by the privacy provisions enacted
17 as a result of the Health Insurance Portability and Ac-
18 countability Act.

19 (b) **REPORT.**—Not later than 18 months after the
20 date of enactment of this Act, the Comptroller General
21 of the United States shall submit to Congress a report
22 on the study conducted under subsection (a) together with
23 recommendations for such legislation and administrative
24 action as the Comptroller General of the United States
25 determines to be appropriate.

1 **SEC. 6. ADVANCE DIRECTIVES AT STATE DEPARTMENT OF**
2 **MOTOR VEHICLES.**

3 Each State shall establish a program of providing in-
4 formation on the advance directives clearinghouse estab-
5 lished pursuant to section 399Z-1 of the Public Health
6 Service Act to individuals who are residents of the State
7 at such State's department of motor vehicles. Such pro-
8 gram shall be modeled after the program of providing in-
9 formation regarding organ donation established at the
10 State's department of motor vehicles, if such State has
11 such an organ donation program.

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