

106TH CONGRESS  
1ST SESSION

# H. R. 1149

To amend titles XVIII and XIX of the Social Security Act to expand and clarify the requirements regarding advance directives in order to ensure that an individual's health care decisions are complied with, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 17, 1999

Mr. LEVIN (for himself, Mr. GREENWOOD, Ms. HOOLEY of Oregon, Mr. GEORGE MILLER of California, Mr. FROST, Mrs. MORELLA, Mrs. MALONEY of New York, Mr. SANDLIN, and Ms. SLAUGHTER) introduced the following bill; which was referred to the Committee on 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

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## A BILL

To amend titles XVIII and XIX of the Social Security Act to expand and clarify the requirements regarding advance directives in order to ensure that an individual's health care decisions are complied with, 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,*

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

2 (a) **SHORT TITLE.**—This Act may be cited as the  
3 “Advance Planning and Compassionate Care Act of  
4 1999”.

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

- Sec. 1. Short title; table of contents.
- Sec. 2. Development of standards to assess end-of-life care.
- Sec. 3. Expansion of advance directives.
- Sec. 4. Study and recommendations to Congress on issues relating to advance  
directive expansion.
- Sec. 5. Study and legislative proposal to Congress.
- Sec. 6. National information hotline for end-of-life decisionmaking.
- Sec. 7. Evaluation of and demonstration projects for innovative and new ap-  
proaches to end-of-life care for medicare beneficiaries.
- Sec. 8. Medicare coverage of self-administered medication for certain patients  
with chronic pain.
- Sec. 9. Annual reports on quality of end-of-life care under the medicare pro-  
gram.

7 **SEC. 2. DEVELOPMENT OF STANDARDS TO ASSESS END-OF-**  
8 **LIFE CARE.**

9 (a) **IN GENERAL.**—The Secretary of Health and  
10 Human Services, through the Administrator of the Health  
11 Care Financing Administration, the Director of the Na-  
12 tional Institutes of Health, and the Administrator of the  
13 Agency for Health Care Policy and Research, shall develop  
14 outcome standards and measures to evaluate the perform-  
15 ance of health care programs and projects that provide  
16 end-of-life care to individuals and the quality of such care.

17 (b) **REPORT TO CONGRESS.**—Not later than 2 years  
18 after the date of the enactment of this Act, the Secretary  
19 of Health and Human Services shall submit a report to

1 Congress regarding the outcome standards and measures  
2 developed pursuant to subsection (a).

3 **SEC. 3. EXPANSION OF ADVANCE DIRECTIVES.**

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

6 (1) in paragraph (1)—

7 (A) in subparagraph (B), by inserting  
8 “and if presented by the individual, to include  
9 the content of such advance directive in a  
10 prominent part of such record” before the semi-  
11 colon;

12 (B) in subparagraph (D), by striking  
13 “and” at the end;

14 (C) in subparagraph (E), by striking the  
15 period and inserting “; and”; and

16 (D) by inserting after subparagraph (E)  
17 the following:

18 “(F) to provide each individual with the oppor-  
19 tunity to discuss issues relating to the information  
20 provided to that individual pursuant to subpara-  
21 graph (A) with an appropriately trained profes-  
22 sional.”; and

23 (2) by adding at the end the following:

24 “(4)(A) An advance directive validly executed outside  
25 of the State in which such advance directive is presented

1 by an adult individual to a provider of services or a pre-  
2 paid or eligible organization shall be given the same effect  
3 by that provider or organization as an advance directive  
4 validly executed under the law of the State in which it  
5 is presented would be given effect.

6 “(B) Nothing in this paragraph shall be construed  
7 to authorize the administration, withholding, or with-  
8 drawal of health care unless it is consistent with the laws  
9 of the State in which an advance directive is presented.

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

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

18 (1) in paragraph (1)—

19 (A) in subparagraph (B)—

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

24 (ii) by inserting “and if presented by  
25 the individual, to include the content of

1           such advance directive in a prominent part  
2           of such record” before the semicolon;

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

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

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

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.”; and

14          (2) by adding at the end the following:

15          “(5)(A) An advance directive validly executed outside  
16          of the State in which such advance directive is presented  
17          by an adult individual to a provider or organization shall  
18          be given the same effect by that provider or organization  
19          as an advance directive validly executed under the law of  
20          the State in which it is presented would be given effect.

21          “(B) Nothing in this paragraph shall be construed  
22          to authorize the administration, withholding, or with-  
23          drawal of health care otherwise prohibited by the laws of  
24          the State in which an advance directive is presented.

1       “(C) The provisions of this paragraph shall preempt  
2 any State law to the extent such law is inconsistent with  
3 such provisions. The provisions of this paragraph shall not  
4 preempt any State law that provides for greater port-  
5 ability, more deference to a patient’s wishes, or more lati-  
6 tude in determining a patient’s wishes.”.

7       (c) EFFECTIVE DATES.—

8           (1) IN GENERAL.—Subject to paragraph (2),  
9 the amendments made by subsections (a) and (b)  
10 shall apply to provider agreements entered into, re-  
11 newed, or extended under title XVIII of the Social  
12 Security Act, and to State plans under title XIX of  
13 such Act, on or after such date (not later than 1  
14 year after the date of the enactment of this Act) as  
15 the Secretary of Health and Human Services speci-  
16 fies.

17           (2) EXTENSION OF EFFECTIVE DATE FOR  
18 STATE LAW AMENDMENT.—In the case of a State  
19 plan under title XIX of the Social Security Act  
20 which the Secretary of Health and Human Services  
21 determines requires State legislation in order for the  
22 plan to meet the additional requirements imposed by  
23 the amendments made by subsection (b), the State  
24 plan shall not be regarded as failing to comply with  
25 the requirements of such title solely on the basis of

1 its failure to meet these additional requirements be-  
2 fore the first day of the first calendar quarter begin-  
3 ning after the close of the first regular session of the  
4 State legislature that begins after the date of the en-  
5 actment of this Act. For purposes of the previous  
6 sentence, in the case of a State that has a 2-year  
7 legislative session, each year of the session is consid-  
8 ered to be a separate regular session of the State  
9 legislature.

10 **SEC. 4. STUDY AND RECOMMENDATIONS TO CONGRESS ON**  
11 **ISSUES RELATING TO ADVANCE DIRECTIVE**  
12 **EXPANSION.**

13 (a) **STUDY.**—The Secretary of Health and Human  
14 Services shall conduct a thorough study regarding the im-  
15 plementation of the amendments made by section 3 of this  
16 Act.

17 (b) **REPORT.**—Not later than 18 months after the  
18 date of enactment of this Act, the Secretary of Health and  
19 Human Services shall submit a report to Congress that  
20 contains a detailed statement of the findings and conclu-  
21 sions of the Secretary regarding the study conducted pur-  
22 suant to subsection (a), together with the Secretary’s rec-  
23 ommendations for such legislation and administrative ac-  
24 tions as the Secretary considers appropriate.

1 **SEC. 5. STUDY AND LEGISLATIVE PROPOSAL TO CONGRESS.**

2 (a) STUDY.—

3 (1) IN GENERAL.—The Secretary of Health and  
4 Human Services shall conduct a thorough study of  
5 all matters relating to the creation of a national uni-  
6 form policy on advance directives for individuals re-  
7 ceiving items and services under titles XVIII and  
8 XIX of the Social Security Act (42 U.S.C. 1395 et  
9 seq., 1396 et seq.).

10 (2) MATTERS STUDIED.—The matters studied  
11 by the Secretary of Health and Human Services  
12 shall include issues concerning—

13 (A) the election or refusal of life-sustaining  
14 treatment;

15 (B) the provision of adequate palliative  
16 care including pain management;

17 (C) the portability of advance directives,  
18 including the cases involving the transfer of an  
19 individual from one health care setting to an-  
20 other;

21 (D) immunity for health care providers  
22 that follow the instructions in an individual's  
23 advance directive;

24 (E) exemptions for health care providers  
25 from following the instructions in an individ-  
26 ual's advance directive;

1 (F) conditions under which an advance di-  
2 rective is operative;

3 (G) revocation of an advance directive by  
4 an individual;

5 (H) the criteria for determining that an in-  
6 dividual is in terminal status; and

7 (I) surrogate decision making regarding  
8 end of life care.

9 (b) REPORT TO CONGRESS.—Not later than 18  
10 months after the date of enactment of this Act, the Sec-  
11 retary of Health and Human Services shall submit a re-  
12 port to Congress that contains a detailed description of  
13 the results of the study conducted pursuant to subsection  
14 (a).

15 (c) CONSULTATION.—In conducting the study and  
16 developing the report under this section, the Secretary of  
17 Health and Human Services shall consult with physicians  
18 and other health care provider groups, consumer groups,  
19 the Uniform Law Commissioners, and other interested  
20 parties.

21 **SEC. 6. NATIONAL INFORMATION HOTLINE FOR END-OF-**  
22 **LIFE DECISIONMAKING.**

23 The Secretary of Health and Human Services,  
24 through the Administrator of the Health Care Financing  
25 Administration, shall establish and operate directly, or by

1 grant, contract, or interagency agreement, out of funds  
2 otherwise appropriated to the Secretary, a clearinghouse  
3 and 24-hour toll-free telephone hotline, to provide con-  
4 sumer information about advance directives, as defined in  
5 section 1866(f)(3) of the Social Security Act (42 U.S.C.  
6 1395cc(f)(3)), and end-of-life decisionmaking.

7 **SEC. 7. EVALUATION OF AND DEMONSTRATION PROJECTS**  
8 **FOR INNOVATIVE AND NEW APPROACHES TO**  
9 **END-OF-LIFE CARE FOR MEDICARE BENE-**  
10 **FICIARIES.**

11 (a) DEFINITIONS.—In this section:

12 (1) MEDICARE BENEFICIARIES.—The term  
13 “medicare beneficiaries” means individuals who are  
14 entitled to benefits under part A or eligible for bene-  
15 fits under part B of the medicare program.

16 (2) MEDICARE PROGRAM.—The term “medicare  
17 program” means the health care program under title  
18 XVIII of the Social Security Act (42 U.S.C. 1395 et  
19 seq.).

20 (3) SECRETARY.—The term “Secretary” means  
21 the Secretary of Health and Human Services.

22 (b) EVALUATION OF EXISTING PROGRAMS.—

23 (1) IN GENERAL.—The Secretary, through the  
24 Administrator of the Health Care Financing Admin-  
25 istration, shall conduct ongoing evaluations of inno-

1 vative health care programs that provide end-of-life  
2 care to medicare beneficiaries who are seriously ill or  
3 who suffer from a medical condition that is likely to  
4 be fatal.

5 (2) REQUIREMENTS.—Evaluations conducted  
6 under this subsection shall include the following:

7 (A) Evidence that the evaluated program  
8 implements practices or procedures that result  
9 in improved patient outcomes, resource utiliza-  
10 tion, or both.

11 (B) A definition of the population served  
12 by the program and a determination as to how  
13 accurately that population reflects the total  
14 medicare beneficiaries in the area who are in  
15 need of services offered by the program.

16 (C) A description of the eligibility require-  
17 ments and enrollment procedures for the pro-  
18 gram.

19 (D) A detailed description of the services  
20 provided to medicare beneficiaries served by the  
21 program and the utilization rates for such serv-  
22 ices.

23 (E) A description of the structure for the  
24 provision of specific services.

1 (F) A detailed accounting of the costs of  
2 providing specific services under the program.

3 (G) A description of any procedures for of-  
4 fering medicare beneficiaries a choice of services  
5 and how the program responds to the pref-  
6 erences of the medicare beneficiaries served by  
7 the program.

8 (H) An assessment of the quality of care  
9 and of the outcomes for medicare beneficiaries  
10 and the families of such beneficiaries served by  
11 the program.

12 (I) An assessment of any ethical, cultural,  
13 or legal concerns regarding the evaluated pro-  
14 gram and with the replication of such program  
15 in other settings.

16 (J) Identification of any changes to regula-  
17 tions, or of any additional funding, that would  
18 result in more efficient procedures or improved  
19 outcomes, for the program.

20 (3) EXTERNAL EVALUATORS.—The Secretary  
21 shall contract with 1 or more external evaluators to  
22 coordinate and conduct the evaluations required  
23 under this subsection and under subsection (c)(4).

24 (4) USE OF OUTCOME MEASURES AND STAND-  
25 ARDS.—An evaluation conducted under this sub-

1 section and subsection (c)(4) shall use the outcome  
2 standards and measures required to be developed  
3 under section 2 as soon as those standards and  
4 measures are available.

5 (c) DEMONSTRATION PROJECTS.—

6 (1) AUTHORITY.—The Secretary, through the  
7 Administrator of the Health Care Financing Admin-  
8 istration, shall conduct demonstration projects to de-  
9 velop new and innovative approaches to providing  
10 end-of-life care to medicare beneficiaries who are se-  
11 riously ill or who suffer from a medical condition  
12 that is likely to be fatal.

13 (2) APPLICATION.—Any entity seeking to con-  
14 duct a demonstration project under this subsection  
15 shall submit to the Secretary an application in such  
16 form and manner as the Secretary may require.

17 (3) SELECTION CRITERIA.—

18 (A) IN GENERAL.—In selecting entities to  
19 conduct demonstration projects under this sub-  
20 section, the Secretary shall select entities that  
21 will allow for demonstration projects to be con-  
22 ducted in a variety of States, in an array of  
23 care settings, and that reflect—

24 (i) a balance between urban and rural  
25 settings;

- 1 (ii) cultural diversity; and  
2 (iii) various modes of medical care  
3 and insurance, such as fee-for-service, pre-  
4 ferred provider organizations, health main-  
5 tenance organizations, hospice care, home  
6 care services, long-term care, and inte-  
7 grated delivery systems.

8 (B) PREFERENCES.—The Secretary shall  
9 give preference to applications for demonstra-  
10 tion projects that—

11 (i) will serve medicare beneficiaries  
12 who are dying of illnesses that are most  
13 prevalent under the medicare program, in-  
14 cluding cancer, heart failure, chronic ob-  
15 structive respiratory disease, dementia,  
16 stroke, and progressive multifactorial frail-  
17 ty associated with advanced age; and

18 (ii) appear capable of sustained serv-  
19 ice and broad replication at a reasonable  
20 cost within commonly available organiza-  
21 tional structures.

22 (4) EVALUATIONS.—Each demonstration  
23 project conducted under this subsection shall be  
24 evaluated at such regular intervals as the Secretary  
25 determines are appropriate. An evaluation of a

1 project conducted under this subsection shall include  
2 the items described in subsection (b)(2) and the fol-  
3 lowing:

4 (A) A comparison of the quality of care  
5 and of the outcomes for medicare beneficiaries  
6 and the families of such beneficiaries served by  
7 the demonstration project to the quality of care  
8 and outcomes for such individuals that would  
9 have resulted if care had been provided under  
10 existing delivery systems.

11 (B) An analysis of how ongoing measures  
12 of quality and accountability for improvement  
13 and excellence could be incorporated into the  
14 demonstration project.

15 (C) A comparison of the costs of the care  
16 provided to medicare beneficiaries under the  
17 demonstration project to the costs of that care  
18 if it had been provided under the medicare pro-  
19 gram.

20 (5) WAIVER AUTHORITY.—The Secretary may  
21 waive compliance with any requirement of titles XI,  
22 XVIII, and XIX of the Social Security Act (42  
23 U.S.C. 1301 et seq., 1395 et seq., 1396 et seq.)  
24 which, if applied, would prevent a demonstration

1 project carried out under this subsection from effec-  
2 tively achieving the purpose of such a project.

3 (d) ANNUAL REPORTS TO CONGRESS.—

4 (1) IN GENERAL.—Beginning 1 year after the  
5 date of enactment of this Act, and annually there-  
6 after, the Secretary shall submit to Congress a re-  
7 port on the quality of end-of-life care under the  
8 medicare program, together with any suggestions for  
9 legislation to improve the quality of such care under  
10 that program.

11 (2) SUMMARY OF RECENT STUDIES.—A report  
12 submitted under this subsection shall include a sum-  
13 mary of any recent studies and advice from experts  
14 in the health care field regarding the ethical, cul-  
15 tural, and legal issues that may arise when attempt-  
16 ing to improve the health care system to meet the  
17 needs of individuals with serious and eventually fatal  
18 illnesses.

19 (3) CONTINUATION OR REPLICATION OF DEM-  
20 ONSTRATION PROJECTS.—Beginning 3 years after  
21 the date of enactment of this Act, the report re-  
22 quired under this subsection shall include rec-  
23 ommendations regarding whether the demonstration  
24 projects conducted under subsection (c) should be

1 continued and whether broad replication of any of  
2 those projects should be initiated.

3 (e) FUNDING.—The Secretary shall provide for the  
4 transfer from the Federal Hospital Insurance Trust Fund  
5 established under section 1817 of the Social Security Act  
6 (42 U.S.C. 1395i) of such sums as are necessary for the  
7 costs of conducting evaluations under subsection (b), con-  
8 ducting demonstration projects under subsection (c), and  
9 preparing and submitting the annual reports required  
10 under subsection (d). Amounts may be transferred under  
11 the preceding sentence without regard to amounts appro-  
12 priated in advance in appropriations Acts.

13 **SEC. 8. MEDICARE COVERAGE OF SELF-ADMINISTERED**  
14 **MEDICATION FOR CERTAIN PATIENTS WITH**  
15 **CHRONIC PAIN.**

16 (a) IN GENERAL.—Section 1861(s)(2) of the Social  
17 Security Act (42 U.S.C. 1395x(s)(2)) is amended—

18 (1) by striking “and” at the end of subpara-  
19 graph (S);

20 (2) in subparagraph (T), by striking the period  
21 at the end and inserting “; and”; and

22 (3) by inserting after subparagraph (T) the fol-  
23 lowing:

24 “(U) self-administered drugs which may be dis-  
25 pensed only upon prescription and which are pre-

1 scribed for the relief of chronic pain in patients with  
2 a life-threatening disease or condition;”.

3 (b) EFFECTIVE DATE.—The amendments made by  
4 subsection (a) shall apply to items and services furnished  
5 on or after January 1, 2000.

6 **SEC. 9. ANNUAL REPORTS ON QUALITY OF END-OF-LIFE**  
7 **CARE UNDER THE MEDICARE PROGRAM.**

8 Beginning 1 year after the date of the enactment of  
9 this Act and annually thereafter, the Secretary of Health  
10 and Human Services shall submit to Congress a report  
11 on the quality of end-of-life care under the medicare pro-  
12 gram. The Secretary shall include in such reports such  
13 recommendations for legislation to improve the quality of  
14 such care under that program as the Secretary deems ap-  
15 propriate.

○