

109TH CONGRESS  
1ST SESSION

# H. R. 4249

To provide for programs within the Department of Health and Human Services and Department of Veterans Affairs for patients with fatal chronic illness, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 8, 2005

Mr. OBERSTAR (for himself and Mr. RAMSTAD) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Ways and Means and Veterans' Affairs, 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 provide for programs within the Department of Health and Human Services and Department of Veterans Affairs for patients with fatal chronic illness, 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 “Living Well with Fatal Chronic Illness Act of 2005”.

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

Sec. 1. Short title; table of contents.

Sec. 2. Department of Health and Human Services programs for patients with  
 fatal chronic illnesses.

Sec. 3. Programs through Department of Veterans Affairs regarding patients  
 with fatal chronic illnesses.

Sec. 4. Study by Institute of Medicine.

3 **SEC. 2. DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
 4 **PROGRAMS FOR PATIENTS WITH FATAL**  
 5 **CHRONIC ILLNESSES.**

6 (a) ESTABLISHMENT OF PROGRAMS.—The Secretary  
 7 of Health and Human Services shall carry out research,  
 8 demonstration, and education programs with respect to  
 9 fatal chronic illness through the Public Health Service.

10 (b) STUDIES ON END-OF-LIFE CARE.—The Sec-  
 11 retary shall conduct studies on end-of-life care through all  
 12 relevant agencies and through the Assistant Secretary for  
 13 Planning and Evaluation. Such studies shall include an  
 14 examination of the development of practice parameters ap-  
 15 plicable to such care as well as research regarding such  
 16 care. Such studies shall also include an annual report from  
 17 the Secretary to the appropriate committees for oversight  
 18 in Congress and to the Special Committee on Aging in  
 19 the Senate on service delivery and quality of life for per-  
 20 sons living through fatal chronic illness and their families  
 21 and professional caregivers.

1       (c) HEALTH RESOURCES AND SERVICES ADMINIS-  
2 TRATION.—

3           (1) IN GENERAL.—In carrying out subsection  
4       (a), the Secretary, acting through the Administrator  
5       of the Health Resources and Services Administra-  
6       tion, shall carry out research, demonstration, and  
7       education programs toward improving the delivery of  
8       appropriate health and support services for patients  
9       with fatal chronic illnesses.

10          (2) HEALTH CENTERS.—As determined appro-  
11       priate by the Secretary, paragraph (1) may be car-  
12       ried out through the program under section 330 of  
13       the Public Health Service Act (relating to commu-  
14       nity and migrant health centers and health centers  
15       regarding homeless individuals and residents of pub-  
16       lic housing), including by designating individuals  
17       with fatal chronic illnesses as medically underserved  
18       populations.

19          (3) CAREGIVERS.—Programs under paragraph  
20       (1) shall include activities regarding appropriate  
21       support services for caregivers for patients with fatal  
22       chronic illness, including respite care.

23          (4) HEALTH PROFESSIONS TRAINING.—Pro-  
24       grams under paragraph (1) shall include making  
25       awards of grants or contracts to public and non-

1 profit private entities for the purpose of training  
2 health professionals, including students attending  
3 health professions schools, in the care of patients  
4 with fatal chronic illnesses. Such training shall in-  
5 clude training in the provision of appropriate pallia-  
6 tive care and appropriate referral to hospices, and  
7 training provided as continuing education.

8 (5) INITIATIVE.—Programs under paragraph  
9 (1) shall include an initiative to coordinate innova-  
10 tion, evaluation, and service delivery relating to fatal  
11 chronic illnesses.

12 (d) AGENCY FOR HEALTHCARE RESEARCH AND  
13 QUALITY.—

14 (1) IN GENERAL.—In carrying out section  
15 912(c) of the Public Health Service Act, the Sec-  
16 retary, acting through the Director of the Agency  
17 for Healthcare Research and Quality, shall, with re-  
18 spect to patients with fatal chronic illnesses—

19 (A) identify the causes of preventable  
20 health care errors and patient injury in health  
21 care delivery, including errors of inadequate  
22 mobilization of services to the home, inadequate  
23 continuity of caregivers, inadequate symptom  
24 prevention, management, and relief, or inad-  
25 equate advance care planning;

1 (B) develop, demonstrate, and evaluate  
2 strategies for reliable performance of the care  
3 system, including reducing errors and improv-  
4 ing patient safety and health outcomes; and

5 (C) disseminate such effective strategies  
6 throughout the health care industry.

7 (2) GRANTS.—In carrying out paragraph  
8 (1)(A), the Secretary shall make grants for the pur-  
9 pose of developing reliable and current data and in-  
10 sight as to the merits and efficiencies of various  
11 strategies for providing health care, including pallia-  
12 tive and hospice care, and social services for patients  
13 with fatal chronic illnesses.

14 (e) CENTERS FOR DISEASE CONTROL AND PREVEN-  
15 TION.—The Director of the Centers for Disease Control  
16 and Prevention shall expand activities with respect to epi-  
17 demiology and public health in fatal chronic illness. Such  
18 activities may include contracting with the Institute of  
19 Medicine or another national interest non-profit organiza-  
20 tion to provide a review of the status of care for the end  
21 of life, which review shall be included by the Secretary in  
22 the annual reports to Congress under subsection (h).

23 (f) NATIONAL INSTITUTES OF HEALTH.—

24 (1) EXPANSION OF ACTIVITIES.—The Director  
25 of the National Institutes of Health (in this sub-

1 section referred to as the “Director”) shall expand,  
2 intensify, and coordinate the activities of the Na-  
3 tional Institutes of Health with respect to research  
4 on fatal chronic illness. Such activities shall include  
5 programs, requests for proposals, study section  
6 membership, advisory council membership, and  
7 training programs to support rapid and substantial  
8 improvements in understanding—

9 (A) mechanisms of disability and suffering  
10 in fatal chronic illness and the relief and man-  
11 agement of that disability and suffering  
12 through to end of life; and

13 (B) human resources, service delivery ar-  
14 rangements, technology, and financing that  
15 would be most useful in ensuring comfort and  
16 dignity for individuals with fatal chronic illness,  
17 and in relieving the burden for family and pro-  
18 fessional caregivers.

19 (2) ADMINISTRATION.—The Director shall  
20 carry out this subsection acting through the Direc-  
21 tors of every Institute within the National Institutes  
22 of Health that has at least one fatal chronic illness  
23 in its purview.

24 (3) COLLABORATION.—In carrying out this sub-  
25 section, the Director of the National Institutes of

1 Health shall collaborate with the Department of Vet-  
2 erans Affairs, the Agency for Healthcare Research  
3 and Quality, and any other agency that the Director  
4 determines appropriate. The Secretary of Veterans  
5 Affairs and the Director of the Agency for  
6 Healthcare Research and Quality shall assist in such  
7 collaboration.

8 (4) RESPONSIBILITIES OF INSTITUTES.—Each  
9 Institute within the National Institutes of Health  
10 that has fatal chronic illness in its purview shall es-  
11 tablish a plan for improving understanding of the  
12 mechanisms of disability and suffering in fatal  
13 chronic illness and the relief and management of  
14 that disability and suffering through to end of life.  
15 Since most Americans now die of chronic heart or  
16 lung failure, cancer, stroke, dementia, or multifacto-  
17 rial frailty, each such Institute shall develop and im-  
18 plement a strategic plan and a set of projects that  
19 aim primarily to ensure that affected patients and  
20 their families can live through advanced illness and  
21 death comfortably and meaningfully.

22 (5) CENTERS OF EXCELLENCE.—

23 (A) IN GENERAL.—In carrying out para-  
24 graph (1), the Director shall make awards of  
25 grants and contracts to public or nonprofit pri-

1 vate entities for the establishment and oper-  
2 ation of centers of excellence to carry out re-  
3 search, demonstration, and education programs  
4 regarding fatal chronic illness, including pro-  
5 grams regarding palliative care.

6 (B) DESIGNATION.—In carrying out this  
7 subsection, the Director shall designate at least  
8 2 Claude D. Pepper Older Americans Independ-  
9 ence Centers (supported by the National Insti-  
10 tute on Aging), 2 program projects of the Na-  
11 tional, Heart, Lung, and Blood Institute, and 2  
12 comprehensive cancer centers (supported by the  
13 National Cancer Institute) to provide education  
14 and information support and research data and  
15 methods leadership for substantial and rapid  
16 improvements in the understanding of the  
17 mechanisms of disability and suffering in fatal  
18 chronic illness and the relief and management  
19 of that disability and suffering through to the  
20 end of life.

21 (C) RESEARCH.—Each center established  
22 or operated under subparagraph (A) or des-  
23 ignated under subparagraph (B) shall conduct  
24 basic and clinical research into fatal chronic ill-  
25 ness.



1 (D) CERTAIN ACTIVITIES.—The Secretary  
2 shall ensure that, with respect to the geographic  
3 area in which a center of excellence under sub-  
4 paragraph (A) is located, the activities of the  
5 center include—

6 (i) providing information and edu-  
7 cation regarding fatal chronic illness to  
8 health professionals and the public;

9 (ii) serving as a resource through  
10 which health professionals, and patients  
11 and their caregivers, can plan and coordi-  
12 nate the provision of health and support  
13 services regarding fatal chronic illness; and

14 (iii) providing training and support of  
15 implementation of quality improvement.

16 (g) MEDICARE PILOT PROGRAMS FOR TREATMENT  
17 OF FATAL CHRONIC ILLNESSES.—

18 (1) ESTABLISHMENT.—The Secretary, in all  
19 relevant parts of the Department of Health and  
20 Human Services, including the Centers for Medicare  
21 & Medicaid Services and the Office of the Assistant  
22 Secretary for Planning and Evaluation, shall provide  
23 for pilot programs under this subsection. The pilot  
24 programs shall be developed under a coordinated na-  
25 tional effort in order to demonstrate innovative, ef-

1       fective means of delivering care to Medicare bene-  
2       ficiaries with fatal chronic illnesses under the Medi-  
3       care program. The pilot programs shall be completed  
4       within 5 years after the date that funds are first ap-  
5       propriated under this subsection.

6               (2) DESIGN.—The pilot programs under this  
7       subsection shall be designed to learn how—

8                       (A) to effectively and efficiently deliver  
9       quality care to the fatally chronically ill;

10                      (B) to provide and maintain continuity of  
11       care for the fatally chronically ill;

12                      (C) to provide advance care planning to  
13       the fatally chronically ill;

14                      (D) to determine what rate and strategies  
15       for payment are most appropriate;

16                      (E) to deliver emergency care for the fa-  
17       tally chronically ill;

18                      (F) to facilitate access to hospice care  
19       when the Medicare beneficiary becomes eligible  
20       for such care;

21                      (G) to develop and estimate the effect of  
22       potential alternative severity criteria for eligi-  
23       bility of specially tailored programs;

24                      (H) to test the effectiveness and costs of  
25       new strategies for family caregivers support;

1 (I) to implement a clinical services and  
2 payment program that uses thresholds of sever-  
3 ity to define the onset of the need for com-  
4 prehensive end-of-life services;

5 (J) to test the merits of using severity cri-  
6 teria (relating to fatal chronic illness) in deter-  
7 mining eligibility for the Medicare hospice pro-  
8 gram, but only when use of such criteria ex-  
9 pands access to hospice care to individuals who  
10 are not yet terminally ill (as that term is de-  
11 fined at section 1861(dd)(3)(A) of the Social  
12 Security Act); and

13 (K) to arrange financial incentives so that  
14 substantially diminished payments arise when  
15 care providers fail to ensure timely advance  
16 care planning, symptom prevention, manage-  
17 ment, and relief, or continuity of care across  
18 time and settings.

19 (3) CONDUCT OF PILOT PROGRAMS.—The Sec-  
20 retary shall conduct pilot programs in at least 6  
21 sites and in at least 3 States.

22 (4) REPORT TO CONGRESS.—The Secretary  
23 shall submit to Congress a report on the pilot pro-  
24 grams under this subsection. Such report shall in-  
25 clude recommendations regarding whether the pilot

1 programs should become a permanent part of the  
2 Medicare program.

3 (h) ANNUAL REPORTS.—The Secretary, in consulta-  
4 tion with the Secretary of Veterans Affairs and other ap-  
5 propriate Federal agencies, shall submit an annual report  
6 to Congress on end-of-life care and on the research, dem-  
7 onstration, and education programs and studies conducted  
8 under this section. The Centers for Disease Control and  
9 Prevention shall be the lead agency for integrating and  
10 preparing the annual reports under this subsection unless  
11 the Secretary designates otherwise.

12 (i) DEFINITIONS.—For purposes of this section:

13 (1) The term “fatal chronic illness” means a  
14 disease (or diseases), condition (or conditions), or  
15 disorder (or disorders) that ordinarily worsens and  
16 causes death and that causes a physical or mental  
17 disability or periodic episodes of significant loss of  
18 functional capacity.

19 (2) The term “Secretary” means the Secretary  
20 of Health and Human Services.

21 (j) AUTHORIZATION OF APPROPRIATIONS.—There  
22 are authorized to be appropriated—

23 (1) such sums as may be necessary to carry out  
24 subsections (a), (b), (e), and (f);

1           (2) \$50,000,000 for the 5-fiscal-year period (be-  
 2           ginning with fiscal year 2006) to carry out sub-  
 3           section (c), excluding paragraph (5) of that sub-  
 4           section;

5           (3) \$100,000,000 for the 3-fiscal-year period  
 6           (beginning with fiscal year 2006) to carry out sub-  
 7           section (c)(5);

8           (4) \$20,000,000 for the 5-fiscal-year period (be-  
 9           ginning with fiscal year 2006) to carry out sub-  
 10          section (d);

11          (5) to carry out subsection (g) for each of fiscal  
 12          years 2006 through 2010—

13               (A) \$50,000,000 for the purposes of con-  
 14               ducting evaluations of pilot programs; and

15               (B) \$50,000,000 for the purpose of pro-  
 16               viding clinical services under pilot programs;  
 17               and

18          (6) \$500,000 for each fiscal year during the 5-  
 19          fiscal-year period beginning with fiscal year 2006 to  
 20          carry out subsection (h).

21 **SEC. 3. PROGRAMS THROUGH DEPARTMENT OF VETERANS**

22                       **AFFAIRS REGARDING PATIENTS WITH FATAL**  
 23                       **CHRONIC ILLNESSES.**

24          (a) IN GENERAL.—

1           (1) VETERANS PROGRAMS.—Chapter 73 of title  
2       38, United States Code, is amended by adding at  
3       the end of subchapter II the following new section:

4   **“§ 7329. Programs for patients with fatal chronic ill-**  
5                           **nesses**

6       “(a) ESTABLISHMENT OF PROGRAMS.—The Sec-  
7   retary shall develop and carry out programs to improve  
8   the delivery of appropriate health and support services for  
9   patients with fatal chronic illnesses. As part of those pro-  
10  grams, the Secretary shall seek to develop services in col-  
11  laboration with community service providers serving popu-  
12  lations of persons other than veterans, especially those  
13  populations that use the Medicare program.

14       “(b) COMMUNITY SERVICE PROVIDERS.—For pur-  
15  poses of this section, a community service provider is an  
16  entity outside the Department that provides health care  
17  services to persons in the community in which it is located.

18       “(c) ROLE OF GRECCs AND HEALTH SERVICES RE-  
19  SEARCH.—The Secretary shall take appropriate steps to  
20  involve in programs under this section both geriatric re-  
21  search, education, and clinical centers under section 7314  
22  of this title and activities of health services research and  
23  quality improvement initiatives of the Department. As  
24  part of those steps, the Secretary shall seek to target the

1 work of such centers and initiatives to improve care for  
2 veterans with fatal chronic illnesses.

3 “(d) TRAINING.—In conducting programs of profes-  
4 sional training and staff development for health-care per-  
5 sonnel of the Department and persons being trained  
6 through health-care programs conducted by the Secretary,  
7 the Secretary shall ensure that those programs include  
8 training in pain relief and end-of-life care for persons with  
9 fatal chronic illnesses. Such training shall address symp-  
10 toms, advance care planning, and quality improvement for  
11 those with fatal chronic illnesses.

12 “(e) ANNUAL REPORT.—The Secretary shall prepare  
13 an annual report on care for veterans with fatal chronic  
14 illnesses and the activities of the Secretary under this sec-  
15 tion. The Secretary shall furnish such report to the Sec-  
16 retary of Health and Human Services each year in suffi-  
17 cient time for inclusion in the annual report of that Sec-  
18 retary under section 2(h) of the Living Well with Fatal  
19 Chronic Illness Act of 2005.

20 “(f) COOPERATION WITH COMMUNITY SERVICE PRO-  
21 VIDERS.—(1) In carrying out this section, the Secretary  
22 shall, to the extent practicable, take appropriate steps,  
23 through collaborative agreements or otherwise, to cooper-  
24 ate with community service providers that provide home  
25 and hospice care.

1       “(2) Such steps shall, to the extent practicable, in-  
2 clude—

3               “(A) developing documentation of advance care  
4 plans for persons with fatal chronic illnesses that are  
5 acceptable to all providers of care for those persons;

6               “(B) developing service programs for persons  
7 with fatal chronic illnesses under which Department  
8 facilities or personnel may be used for part of the  
9 array of services provided to such persons; and

10              “(C) developing protocols that facilitate the  
11 placement with community service providers sup-  
12 ported by the medicare or medicaid programs of vet-  
13 erans with fatal chronic illnesses when such a place-  
14 ment would be more efficient or effective for the  
15 timely provision of services for the community in  
16 which the facilities are located and for such veterans  
17 than the provision of those services directly through  
18 Department facilities.

19       “(3) When the Secretary, as part of service programs  
20 authorized by this subsection, provides services to a person  
21 with a fatal chronic illness who is not a veteran, the Sec-  
22 retary shall, as a condition of providing such services, be  
23 reimbursed by appropriate community service providers  
24 for the costs of such services.



1       “(g) SUPPORT FOR VOLUNTEER AND COMMUNITY  
 2 SUPPORT OF VETERANS LIVING AT HOME.—The Sec-  
 3 retary shall make grants to support volunteer and commu-  
 4 nity support of veterans living at home who have fatal  
 5 chronic illnesses. The Secretary may establish the min-  
 6 imum number of volunteers an entity must have in order  
 7 to be eligible for a grant under this subsection.

8       “(h) FATAL CHRONIC ILLNESS DEFINED.—For pur-  
 9 poses of this section, the term ‘fatal chronic illness’ means  
 10 a disease (or diseases), condition (or conditions), or dis-  
 11 order (or disorders) that ordinarily worsens and causes  
 12 death and that causes a physical or mental disability or  
 13 periodic episodes of significant loss of functional capac-  
 14 ity.”.

15               (2) CLERICAL AMENDMENT.—The table of sec-  
 16 tions at the beginning of such chapter is amended  
 17 by inserting after the item relating to section 7328  
 18 the following new item:

“7329. Programs for patients with fatal chronic illnesses.”.

19       (b) AUTHORIZATION OF APPROPRIATIONS.—There  
 20 are authorized to be appropriated to the Secretary of Vet-  
 21 erans Affairs to carry out section 7329 of title 38, United  
 22 States Code, as added by subsection (a), the amount of  
 23 \$5,000,000 for each of fiscal years 2006 through 2010.

1 **SEC. 4. STUDY BY INSTITUTE OF MEDICINE.**

2 (a) STUDY.—The Secretary of Health and Human  
3 Services shall request the Institute of Medicine of the Na-  
4 tional Academy of Sciences to enter into an agreement  
5 under which the Institute agrees to conduct a study on  
6 the following:

7 (1) The level of care for the elderly provided by  
8 family members.

9 (2) The coordination of care for the elderly pro-  
10 vided by family members with more formal care pro-  
11 vided by health care providers.

12 (b) REPORT.—The Secretary of Health and Human  
13 Services shall ensure that the agreement under subsection  
14 (a) provides for the submission of a report to the Con-  
15 gress, not later than one year after the date of the enact-  
16 ment of this Act, on the results of the study conducted  
17 under this section.

○