I

118TH CONGRESS
2D SESSION

H. R. 9237

To improve end-of-life care.

IN THE HOUSE OF REPRESENTATIVES

AUGUST 2, 2024

Ms. BARRAGÁN 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 improve end-of-life care.

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.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 "Compassionate Care Act".

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

Sec. 1. Short title.
Sec. 2. Definitions.

TITLE I—ADVANCE CARE PLANNING

Subtitle A—Consumer Education

Sec. 101. Advance care planning guidelines.
Sec. 102. National public education campaign.

Subtitle B—Provider Education

Sec. 111. Public provider advance care planning website.
Sec. 112. Advance care curricula pilot program.
Sec. 113. Development of core end-of-life care quality measures across each relevant provider setting.
Sec. 114. Continuing education for qualified health care providers.

Subtitle C—Medicare Amendments

Sec. 121. Permanent extension of authorization for use of telehealth to conduct face-to-face encounter prior to recertification of eligibility for hospice care.
Sec. 122. Improvements to advance care planning through telehealth.

TITLE II—REPORTS, RESEARCH, AND EVALUATIONS

Sec. 201. Study and report by the Secretary regarding the establishment and implementation of a national uniform policy on advance directives.
Sec. 202. Gao study and report on establishment of national advance directive registry; other studies.

1 **SEC. 2. DEFINITIONS.**

2 In this Act:

3 (1) ADVANCE CARE PLANNING.—The term "ad-
4 vance care planning" means the process of discus-
5 sion of care in the event that an individual is unable
6 to make treatment decisions on their own behalf,
7 clarification of related values and goals, and embodi-
8 ment of preferences and decision making through
9 written documents and medical orders.

10 (2) ADVANCE DIRECTIVE.—The term "advance
11 directive" means a written or otherwise recorded in-
12 struction, such as a living will or durable power of
13 attorney for health care, recognized under the law of
14 the State in which it was executed (whether statu-

1 tory or as recognized by the courts of the State) and
2 relating to the provision of such care when the indi-
3 vidual is incapacitated.

4 (3) CERTIFIED CHAPLAIN.—The term ''certified
5 chaplain'' means a member of clergy who has met
6 the requirements under the Common Qualifications
7 and Competencies for Professional Chaplains and
8 has is board certified by a national chaplaincy orga-
9 nization.

10 (4) CHIP.—The term ''CHIP'' means the
11 State Children's Health Insurance Program under
12 title XXI of the Social Security Act (42 U.S.C.
13 1397aa et seq.)

14 (5) END-OF-LIFE-CARE.—The term ''end-of-life
15 care'' means all aspects of care of a patient with a
16 potentially fatal condition, and includes care that is
17 focused on preparations for an impending death.

18 (6) HEALTH CARE AGENT.—The term ''health
19 care agent'' means the person, designated in a
20 health care power of attorney, who is selected to
21 make medical decisions on behalf of the person who
22 executed such power of attorney, in the case of inca-
23 pacity of such person who executed the power of at-
24 torney.

1 (7) HEALTH CARE POWER OF ATTORNEY.—The
2 term ''health care power of attorney'' means a legal
3 document that identifies the health care agent of the
4 person executing such document.
5 (8) LIVING WILL.—The term ''living will''
6 means a written document or a video statement
7 about the kinds of medical care or other care a per-
8 son does or does not want under certain specific con-
9 ditions, in the event that such person no longer is
10 able to express those wishes.
11 (9) MEDICAID.—The term ''Medicaid'' means
12 the program established under title XIX of the So-
13 cial Security Act (42 U.S.C. 1396 et seq.).
14 (10) MEDICARE.—The term ''Medicare'' means
15 the program established under title XVIII of the So-
16 cial Security Act (42 U.S.C. 1395 et seq.).
17 (11) ORDERS FOR LIFE-SUSTAINING TREAT-
18 MENT.—The term ''orders for life-sustaining treat-
19 ment'' means a set of portable medical orders (such
20 as physician orders for life-sustaining treatment or
21 similar portable medical orders) that address key
22 medical decisions consistent with the patient's goals
23 of care and results from a clinical process designed
24 to facilitate shared, informed medical decision-
25 making and communication between qualified health

1 care professionals and patients with serious, progres-
2 sive illness or frailty.

3 (12) QUALIFIED HEALTH CARE PROVIDER.—
4 The term "qualified health care provider" means a
5 medical doctor, doctor of osteopathy, nurse, physi-
6 cian assistant, nurse practitioner, social worker,
7 home health aide, palliative care professional, com-
8 munity health worker, community health educator,
9 or individual in a similar position, as designated by
10 the Secretary.

11 (13) SECRETARY.—The term "Secretary"
12 means the Secretary of Health and Human Services.

13 TITLE I—ADVANCE CARE 14 PLANNING

15 Subtitle A—Consumer Education

16 SEC. 101. ADVANCE CARE PLANNING GUIDELINES.

17 It is the sense of the Senate that, to the extent prac-
18 ticable, advance care planning should—

19 (1) occur with an individual and such individ-
20 ual's health care agent, primary clinician, other au-
21 thorized decisionmaker, or members of the entire
22 interdisciplinary health care team;

23 (2) be recorded and updated as needed; and

24 (3) allow for flexible decisionmaking in the con-
25 text of the patient's medical situation, in accordance

1 with best practice guidelines provided by the Sec-
2 retary.

3 **SEC. 102. NATIONAL PUBLIC EDUCATION CAMPAIGN.**

4 (a) NATIONAL PUBLIC EDUCATION CAMPAIGN.—

5 (1) IN GENERAL.—Not later than January 1,
6 2024, the Secretary, acting through the Director of
7 the Centers for Disease Control and Prevention and
8 in consultation with public and private entities,
9 shall, directly or through grants, contracts, or inter-
10 agency agreements, develop and implement a na-
11 tional campaign to inform the public of the impor-
12 tance of advance care planning and of an individ-
13 ual's right to direct and participate in health care
14 decisions affecting such individual.

15 (2) CONTENT OF EDUCATIONAL CAMPAIGN.—
16 The national public education campaign established
17 under paragraph (1) shall—

18 (A) employ the use of various media, in-
19 cluding social media platforms and televised
20 public service announcements;

21 (B) provide culturally and linguistically ap-
22 propriate information;

23 (C) be conducted continuously over a pe-
24 riod of not less than 5 years;

1 (D) identify and promote the advance care
2 planning information available on the Internet
3 Websites of the Department of Health and
4 Human Service's National Clearinghouse for
5 Long-Term Care Information, the Administra-
6 tion for Children and Families, the Administra-
7 tion for Community Living, and the Centers for
8 Medicare & Medicaid Services;
9 (E) address the importance of individuals
10 speaking to family members, health care prox-
11 ies, and qualified health care providers as part
12 of an ongoing dialogue regarding health care
13 choices;
14 (F) address the need for individuals to use
15 portable, interoperable, and accessible methods
16 to communicate their health care decisions
17 through a variety of means, using legally effec-
18 tuated documents that express their health care
19 decisions in the form of advance directives (in-
20 cluding living wills, orders for life-sustaining
21 treatment, and durable powers of attorney for
22 health care);
23 (G) raise public awareness regarding the
24 availability of hospice and palliative care and

1 the quality of life benefits of early use of such
2 services;
3 (H) encourage individuals to speak with
4 qualified health care professionals about their
5 options and intentions for end-of-life care; and
6 (I) adhere to evidence-based research on
7 the most effective ways to communicate the ne-
8 cessity and benefits of advance care planning.
9 (3) EVALUATION.—Not later than July 1,
10 2026, the Secretary shall report to the appropriate
11 committees of Congress on the effectiveness of the
12 public education campaign under this section, and
13 include in such report any recommendations that the
14 Secretary determines appropriate regarding the need
15 for continuation of legislative or administrative
16 changes to facilitate changing public awareness, atti-
17 tudes, and behaviors regarding advance care plan-
18 ning.
19 (4) AUTHORIZATION OF APPROPRIATIONS.—
20 There are authorized to be appropriated such sums
21 as may be necessary to carry out this section.
22 (b) REPEAL.—Section 4751(d) of the Omnibus
23 Budget Reconciliation Act of 1990 (42 U.S.C. 1396a note;
24 Public Law 101–508) is repealed.

Subtitle B—Provider Education

SEC. 111. PUBLIC PROVIDER ADVANCE CARE PLANNING WEBSITE.

(a) DEVELOPMENT.—Not later than January 1, 2025, the Secretary, acting through the Administrator of the Centers for Medicare & Medicaid Services and the Director of the Agency for Healthcare Research and Quality, shall establish an, or expand upon an existing, internet website for providers under Medicare, Medicaid, CHIP, the Indian Health Service (including contract providers), and other qualified health care providers, including qualified health care providers receiving assistance under the Older Americans Act of 1965 (42 U.S.C. 3002 et seq.) to serve older individuals, on each individual's right to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment, and engage in advance care planning.

(b) MAINTENANCE.—The internet website described in subsection (a) shall be maintained and publicized by the Secretary on an ongoing basis.

(c) CONTENT.—The internet website shall include content, tools, and resources necessary to do the following:

(1) Inform qualified health care providers and certified chaplains about the advance directive requirements under the health care programs de-

1 scribed in subsection (a) and State and Federal laws
2 and regulations related to advance care planning.
3 (2) Educate qualified health care providers and
4 certified chaplains about advance care planning
5 quality improvement activities.
6 (3) Provide assistance to qualified health care
7 providers to—
8 (A) integrate advance care planning docu-
9 ments into electronic health records; and
10 (B) develop and disseminate advance care
11 planning informational materials for patients.
12 (4) Inform qualified health care providers about
13 advance care planning continuing education require-
14 ments and opportunities.
15 (5) Encourage qualified health care providers to
16 discuss advance care planning with patients of all
17 ages, as appropriate.
18 (6) Assist qualified health care providers and
19 certified chaplains in understanding the continuum
20 of end-of-life care services and supports available to
21 patients, including palliative care and hospice.
22 (7) Inform qualified health care providers of
23 best practices for discussing end-of-life care with pa-
24 tients who have a serious or terminal diagnosis or
25 prognosis and their loved ones.

1 **SEC. 112. ADVANCE CARE CURRICULA PILOT PROGRAM.**

2 (a) IN GENERAL.—The Secretary, in consultation
3 with appropriate professional associations, shall establish
4 a pilot program by which the Secretary awards grants to
5 eligible entities for purposes of supporting such entities
6 in establishing end-of-life training requirements in the en-
7 tities' applicable degree programs.

8 (b) ELIGIBILITY.—To be eligible to participate in the
9 pilot program under this section, an entity shall—

10 (1) be a school of medicine, school of osteo-
11 pathic medicine, a physician assistant education pro-
12 gram (as defined in section 799B(3) of the Public
13 Health Service Act (42 U.S.C. 295p(3))), a school of
14 allied health (as defined in section 799B(4) of the
15 Public Health Service Act (42 U.S.C. 295p(4))), a
16 school of nursing, a school of social work, a graduate
17 medical education program accredited by the Accred-
18 itation Council for Graduate Medical Education or
19 the American Osteopathic Association, or other
20 school, as the Secretary determines appropriate;

21 (2) be staffed by teaching health professionals
22 who have experience or training in palliative medi-
23 cine;

24 (3) provide training in palliative medicine
25 through a variety of service rotations, such as con-
26 sultation services, acute care services, extended care

1 facilities, ambulatory care and comprehensive eval-
2 uation units, hospice, home health, and community
3 care programs;
4 (4) develop specific performance-based meas-
5 ures to evaluate the competency of trainees; and
6 (5) ensure that by not later than the end of the
7 2-year period beginning on the date of enactment of
8 this Act, professionals who are applicable faculty at
9 the entity, or others as determined appropriate by
10 the Secretary, shall be offered retraining in hospice
11 and palliative medicine.
12 (c) TRAINING.—Eligible entities participating in the
13 pilot program under this section shall require minimum
14 training for trainees that includes—
15 (1) training in how to discuss and help patients
16 and their loved ones with advance care planning;
17 (2) with respect to trainees who will work with
18 children, specialized pediatric training;
19 (3) training in the continuum of end-of-life
20 services and supports, including palliative care and
21 hospice;
22 (4) training in how to discuss end-of-life care
23 with dying patients and their loved ones;
24 (5) medical and legal issues training associated
25 with end of life care;

1 (6) training in linguistic and cultural com-
2 petency; and
3 (7) in the case of a graduate medical education
4 program accredited by the Accreditation Council for
5 Graduate Medical Education or the American Osteo-
6 pathic Association, a longitudinal component of at
7 least 6 months.
8 (d) REPORTS.—Each recipient of a grant under this
9 section shall report to the Secretary on the outcomes of
10 the program within 18 months of receipt of the final allot-
11 ment of grant funds. Not later than 1 year after receipt
12 of all such reports, the Secretary shall submit to Congress
13 a report compiling such results from all grant recipients.
14 (e) AUTHORIZATION OF APPROPRIATIONS.—There
15 are authorized to be appropriated such sums as may be
16 necessary to carry out this section.
17 **SEC. 113. DEVELOPMENT OF CORE END-OF-LIFE CARE**
18 **QUALITY MEASURES ACROSS EACH REL-**
19 **EVANT PROVIDER SETTING.**
20 (a) IN GENERAL.—The Secretary, acting through the
21 Director of the Agency for Healthcare Research and Qual-
22 ity (in this section referred to as the ‘‘Director’’) and in
23 consultation with the Administrator of the Centers for
24 Medicare & Medicaid Services, shall require the develop-
25 ment of specific end-of-life quality measures for each rel-

1 evant qualified health care provider setting, as identified
2 by the Director, in accordance with the requirements of
3 subsection (b).

4 (b) REQUIREMENTS.—For purposes of subsection
5 (a), the requirements specified in this subsection are the
6 following:

7 (1) Selection of the specific measure or meas-
8 ures for an identified provider setting shall be based
9 on an assessment of what is likely to have the great-
10 est positive impact on quality of end-of-life care in
11 that setting, and made in consultation with affected
12 providers, patients, and private organizations, that
13 have developed such measures.

14 (2) The measures may be structure-oriented,
15 process-oriented, or outcome-oriented, as determined
16 appropriate by the Director, and shall be patient-ori-
17 ented.

18 (3) The Director shall ensure that reporting re-
19 quirements related to such measures—

20 (A) are imposed consistently with other ap-
21 plicable laws and regulations, and in a manner
22 that takes into account existing measures, the
23 needs of patient populations, the specific serv-
24 ices provided, and the potential administrative
25 burden to providers; and

1 (B) include demographic information to account for race, ethnicity, age, and gender, and other appropriate categories.

4 (4) Not later than—

5 (A) January 1, 2024, the Secretary shall disseminate the reporting requirements to all affected providers and provide for a 60-day period for public comment; and

9 (B) January 1, 2026, initial reporting by health care providers relating to the measures shall begin.

12 **SEC. 114. CONTINUING EDUCATION FOR QUALIFIED HEALTH CARE PROVIDERS.**

14 (a) IN GENERAL.—Not later than January 1, 2024, the Secretary, acting through the Administrator of the Health Resources and Services Administration, shall develop or enhance new and existing curricula on advance care planning and end-of-life care for continuing education that States may adopt for qualified health care providers.

20 (b) CONSULTATION.—In carrying out subsection (a), the Secretary, acting through the Administrator of the Health Resources and Services Administration, may consult with qualified health care providers, applicable professional clinician associations, institutions of higher edu-

1 cation, State boards of medicine and nursing, and other
2 professionals, as the Secretary determines appropriate.
3 (c) CONTENT.—The continuing education curriculum
4 developed or enhanced under subsection (a) shall, at a
5 minimum, include—
6 (1) a description of the meaning and impor-
7 tance of advance care planning;
8 (2) a description of advance care planning doc-
9 uments, including living wills and durable powers of
10 attorney, and the use of such directives;
11 (3) the appropriate use of orders for scope of
12 treatment;
13 (4) counseling skills for when and how to intro-
14 duce and engage in advance care planning with pa-
15 tients and their loved ones;
16 (5) palliative care principles and approaches to
17 care;
18 (6) the continuum of end-of-life services and
19 supports, including palliative care and hospice; and
20 (7) the importance of introducing palliative care
21 and hospice early in illness in order to improve qual-
22 ity of life.

1 # Subtitle C—Medicare Amendments

2 **SEC. 121. PERMANENT EXTENSION OF AUTHORIZATION**
3 **FOR USE OF TELEHEALTH TO CONDUCT**
4 **FACE-TO-FACE ENCOUNTER PRIOR TO RE-**
5 **CERTIFICATION OF ELIGIBILITY FOR HOS-**
6 **PICE CARE.**

7 Section 1814(a)(7)(D)(i)(II) of the Social Security
8 Act (42 U.S.C. 1395f(a)(7)(D)(i)(II)) is amended by
9 striking ‘‘during the emergency period’’ and all that fol-
10 lows through ‘‘ending on December 31, 2024’’ and insert-
11 ing the following: ‘‘during and after the emergency period
12 described in section 1135(g)(1)(B)’’.

13 **SEC. 122. IMPROVEMENTS TO ADVANCE CARE PLANNING**
14 **THROUGH TELEHEALTH.**

15 Section 1834(m) of the Social Security Act (42
16 U.S.C. 1395m(m)) is amended—
17 (1) in paragraph (4)(C)—
18 (A) in clause (i), in the matter preceding
19 subclause (I), by striking ‘‘and (7)’’ and insert-
20 ing ‘‘(7), and (10)’’; and
21 (B) in clause (ii)(X), by inserting ‘‘or
22 paragraph (10)’’ before the period; and
23 (2) by adding at the end the following new
24 paragraph:

"(10) TREATMENT OF ADVANCE CARE PLANNING SERVICES.—The geographic requirements described in paragraph (4)(C)(i) shall not apply with respect to telehealth services furnished on or after January 1, 2024, for purposes of furnishing advance care planning services, as determined by the Secretary.".

TITLE II—REPORTS, RESEARCH, AND EVALUATIONS

SEC. 201. STUDY AND REPORT BY THE SECRETARY REGARDING THE ESTABLISHMENT AND IMPLEMENTATION OF A NATIONAL UNIFORM POLICY ON ADVANCE DIRECTIVES.

(a) STUDY.—

(1) IN GENERAL.—The Secretary, acting through the Office of the Assistant Secretary for Planning and Evaluation, shall conduct a study to evaluate the barriers to establishing and implementing a national uniform policy on advance directives and what needs to be done to overcome those barriers.

(2) MATTERS STUDIED.—The matters studied by the Secretary under paragraph (1) shall include issues concerning—

1 (A) family satisfaction that a patient's
2 wishes, as stated in the patient's advance direc-
3 tive, were carried out;
4 (B) the usability, accessibility, interoper-
5 ability, and portability of advance directives, in-
6 cluding cases involving the transfer of an indi-
7 vidual from one health care setting to another;
8 (C) the feasibility of establishing an op-
9 tional, national advance directive form deemed
10 valid by any health care entity or qualified
11 health care provider participating in Medicare,
12 Medicaid, or CHIP, regardless of State law;
13 and
14 (D) State variations in advance directive
15 laws that are relevant to the establishment and
16 implementation of a national uniform policy of
17 advance directives.
18 (b) REPORT TO CONGRESS.—Not later than 2 years
19 after the date of enactment of this Act, the Secretary shall
20 submit to Congress a report on the study conducted under
21 subsection (a), together with recommendations for such
22 legislation and administrative actions as the Secretary
23 considers appropriate.
24 (c) CONSULTATION.—In conducting the study and
25 developing the report under this section, the Secretary

1 shall consult with relevant stakeholders and other inter-
2 ested parties.

3 **SEC. 202. GAO STUDY AND REPORT ON ESTABLISHMENT OF**
4 **NATIONAL ADVANCE DIRECTIVE REGISTRY;**
5 **OTHER STUDIES.**

6 (a) STUDY AND REPORT ON ESTABLISHMENT OF NA-
7 TIONAL ADVANCE DIRECTIVE REGISTRY.—

8 (1) STUDY.—The Comptroller General of the
9 United States shall conduct a study on the feasi-
10 bility of a national registry for advance directives,
11 taking into consideration the constraints created by
12 the privacy provisions enacted as a result of the
13 Health Insurance Portability and Accountability Act
14 of 1996 (Public Law 104–191).

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

23 (b) ONC STUDY.—The National Coordinator of the
24 Office of the National Coordinator for Health Information
25 Technology shall conduct a study on the feasibility and

1 impact on advance care planning of requiring that elec-
2 tronic health record vendors seeking certification have a
3 prominent and easily visible field for storing and sharing
4 advance care planning documents and related clinical
5 notes.

6 (c) ONC DEMONSTRATION PROGRAMS.—The Na-
7 tional Coordinator for Health Information Technology, in
8 collaboration with the Director of the National Institute
9 of Standards and Technology, shall initiate 2 demonstra-
10 tion programs to establish best practices and rec-
11 ommended standards to support—

12 (1) usability, portability and interoperability of
13 advance directives that are accessible to individuals,
14 clinicians, and other authorized individuals; and

15 (2) the use of electronic signatures, electronic
16 authentication of witnesses, and electronic notariza-
17 tion to effectuate advance directives.

18 (d) ADDITIONAL STUDY.—The Comptroller General
19 of the United States shall conduct a study and submit a
20 report to Congress on the incidence of health care, tests,
21 surgeries, drugs, and other services paid provided by quali-
22 fied health care providers and paid for by the Federal Gov-
23 ernment or the patient and that were not the preference

1 of the patient or the authorized health care agent of the
2 patient.

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