

114TH CONGRESS
2D SESSION

H. R. 5555

To amend titles XVIII and XIX of the Social Security Act to improve
end-of-life care and advanced illness management.

IN THE HOUSE OF REPRESENTATIVES

JUNE 22, 2016

Mr. BLUMENAUER (for himself and Mr. ROE of Tennessee) 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
to improve end-of-life care and advanced illness management.

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; FINDINGS; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Personalize Your Care Act 2.0”.

6 (b) FINDINGS.—Congress finds the following:

1 (1) All individuals should be afforded the oppor-
2 tunity to fully participate in decisions related to
3 their health care.

4 (2) Care near the end of life should be person-
5 and family-oriented and evidence-based.

6 (3) To ensure high-quality, person-centered care
7 near the end of life, care must align with an individ-
8 ual's goals, values, and stated preferences.

9 (4) Advance care planning plays a valuable role
10 in achieving quality care by informing providers and
11 family members of an individual's treatment pref-
12 erences.

13 (5) All clinicians who care for people with ad-
14 vanced serious illness should demonstrate com-
15 petence in basic advance care planning and palliative
16 care, including communication skills, inter-profes-
17 sional collaboration, and symptom management.

18 (6) More should be done to establish specific
19 policies and programs to assist people with sensory,
20 mental, and other disabilities in order to maximize
21 the degree to which they are active participants in
22 the decisions related to their health care, including
23 training health care providers how to communicate
24 with people with developmental, psychiatric, speech,
25 and sensory disabilities.

1 (7) Including completed advance care planning
 2 documents within a patient’s electronic health record
 3 can increase the likelihood these documents are kept
 4 current and available at the right place at the right
 5 time.

6 (8) A decade of research has demonstrated that
 7 physician orders for life-sustaining treatment effec-
 8 tively convey patient preferences and guide medical
 9 personnel toward medical treatment aligned with pa-
 10 tient wishes.

11 (9) Patients, caregivers, families, and health
 12 professionals would benefit from an authoritative,
 13 validated list of core components to the delivery
 14 high-quality end-of-life care.

15 (10) Palliative care, hospice, and various care
 16 models that integrate health care and supportive
 17 services provide high-quality end-of-life care and re-
 18 duce the use of avoidable hospital- and institution-
 19 based services that the patient does not want.

20 (c) TABLE OF CONTENTS.—The table of contents of
 21 this Act is as follows:

Sec. 1. Short title; findings; table of contents.

Sec. 2. Advanced illness management and choices care model demonstration program.

Sec. 3. Grants for programs for orders for life-sustaining treatment and similar provider or medical orders.

Sec. 4. Advance care planning standards for electronic health records.

Sec. 5. Portability of advance directives.

Sec. 6. Application of quality measures under Medicare relating to end-of-life care.

Sec. 7. Annual report on Medicare decedents.

Sec. 8. Grants to increase public awareness of advance care planning.

Sec. 9. Advance care planning and palliative care education and training.

Sec. 10. Advance Care Planning Advisory Council.

1 **SEC. 2. ADVANCED ILLNESS MANAGEMENT AND CHOICES**

2 **CARE MODEL DEMONSTRATION PROGRAM.**

3 (a) IN GENERAL.—The Secretary of Health and
 4 Human Services (in this section referred to as the “Sec-
 5 retary”) shall establish a 3-year demonstration program
 6 (in this section referred to as the “demonstration pro-
 7 gram”) to test the use of advanced illness management
 8 and early use of palliative care under the Medicare pro-
 9 gram. The Secretary may extend the program to a dura-
 10 tion of 4 or 5 years, as determined necessary by the Sec-
 11 retary in coordination with the Centers for Medicare and
 12 Medicaid Innovation.

13 (b) DEMONSTRATION PROGRAM DESIGN.—Under the
 14 demonstration program the Secretary shall establish a
 15 capitated payment for the payment of advanced illness
 16 management services and the early use of palliative care
 17 consistent with the following:

18 (1) The services and care are furnished to indi-
 19 viduals who—

20 (A) reside at home or in an institutional
 21 setting;

1 (B) have a documented medical prognosis
2 that the individual's life expectancy is 24
3 months or less; and

4 (C) have the need for assistance with two
5 or more activities of daily living or meet such
6 other criteria as the Secretary may specify.

7 (2) The services and care are furnished concur-
8 rently with the receipt of services related to the
9 treatment of the individual's condition with respect
10 to which a diagnosis of terminal illness has been
11 made.

12 (3) The services and care include at least hos-
13 pice care (as defined in section 1861(dd)(1) of the
14 Social Security Act), a functional assessment of the
15 individual and of the family caregiver (as appro-
16 priate), in-home services and supports, 24-hour, 7-
17 day-a-week emergency supports, care coordination
18 and communication across settings and providers,
19 and such other palliative care services as the Sec-
20 retary deems necessary.

21 (4) The services and care are furnished by an
22 interdisciplinary team that includes primary care
23 providers, palliative medicine specialists, palliative
24 nurses, social workers, chaplains, pharmacists, dieti-
25 cians, physical therapists, occupational therapists,

(c) **TIMELY IMPLEMENTATION.**—The Secretary of Health and Human Services shall implement a capitated payment model for the payment of advanced illness management services under subsection (a) not later than 2 years after the date of the enactment of this Act.

(a) IN GENERAL.—The Secretary of Health and Human Services shall make grants to eligible entities for the purpose of developing, expanding, and enhancing programs for orders for life-sustaining treatment (as defined in subsection (c)(2)).

(b) AUTHORIZED ACTIVITIES.—Activities funded through a grant under this section for an area may include—

(1) developing such a program for the area that includes hospitals, home care, hospice, long-term care, community and assisted living residences, skilled nursing facilities, and emergency medical services within a State;

(2) expanding an existing program for orders
regarding life-sustaining treatment to serve more pa-

1 tients or enhance the quality of services, including
2 educational services for patients and patients' fami-
3 lies, training of health care professionals, or estab-
4 lishing an orders for life-sustaining treatment reg-
5 istry; and

6 (3) technical assistance and professional train-
7 ing.

8 (c) DEFINITIONS.—In this section:

9 (1) The term “eligible entity” includes—

10 (A) an academic medical center, a medical
11 school, a State health department, a State med-
12 ical association, a multistate task force, a hos-
13 pital, or a health system capable of admin-
14 istering a program for physician orders regard-
15 ing life-sustaining treatment for a State; or

16 (B) any other health care agency or entity
17 as the Secretary determines appropriate.

18 (2) The term “program for orders for life-sus-
19 taining treatment” means a program that, regard-
20 less of its name—

21 (A) implements a clinical process designed
22 to facilitate shared, informed medical decision-
23 making and communication between health care
24 professionals and patients with serious, progres-
25 sive illness or frailty and results in a set of

1 medical orders that are substantially consistent
2 with the national standard and that—

3 (i) are portable and honored across
4 care settings; and

5 (ii) address key medical decisions con-
6 sistent with the patient’s goals of care; and

7 (B) is guided by a coalition of stake-
8 holders, such as patient advocacy groups and
9 representatives from across the continuum of
10 health care services, disability rights advocates,
11 senior advocates, emergency medical services,
12 long-term care, medical associations, hospitals,
13 home health, hospice, nursing associations, the
14 State agency responsible for senior and dis-
15 ability services, faith-based groups, and the
16 State department of health.

17 (3) The term “Secretary” means the Secretary
18 of Health and Human Services.

19 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
20 out this section, there are authorized to be appropriated
21 \$35,000,000 for the 5-fiscal-year period beginning with
22 fiscal year 2017, to remain available until expended.

1 **SEC. 4. ADVANCE CARE PLANNING STANDARDS FOR ELEC-**
 2 **TRONIC HEALTH RECORDS.**

3 (a) IN GENERAL.—Notwithstanding section
 4 3004(b)(3) of the Public Health Service Act (42 U.S.C.
 5 300jj–14(b)(3)), not later than 4 years after the date of
 6 the enactment of this Act, the Secretary of Health and
 7 Human Services shall adopt, by rule, standards for a
 8 qualified electronic health record (as defined in section
 9 3000(13) of such Act (42 U.S.C. 300jj(13)), with respect
 10 to organizing patient communications with health care
 11 providers about care goals and to provide one-click access
 12 to the following:

13 (1) The patient’s current advance directive (as
 14 defined in section 1866(f)(3) of the Social Security
 15 Act (42 U.S.C. 1395cc(f)(3)), as applicable.

16 (2) The patient’s current order for life-sus-
 17 taining treatment (described in section 3(c)(2)(A)),
 18 as applicable.

19 (3) Documentation of advance care planning
 20 discussion between the patient and the provider.

21 (b) TREATMENT OF STANDARDS.—A standard adopt-
 22 ed under subsection (a) shall be treated as a standard
 23 adopted under section 3004 of the Public Health Service
 24 Act (42 U.S.C. 300jj–14) for purposes of certifying quali-
 25 fied electronic health records pursuant to section
 26 3001(c)(5) of such Act (42 U.S.C. 300jj–11(c)(5)).

1 **SEC. 5. PORTABILITY OF ADVANCE DIRECTIVES.**

2 (a) IN GENERAL.—Section 1866(f) of the Social Se-
3 curity Act (42 U.S.C. 1395cc(f)) is amended by adding
4 at the end the following new paragraph:

5 “(5)(A) An advance directive validly executed outside
6 the State in which such directive is presented must be
7 given effect by a provider of services or organization to
8 the same extent as an advance directive validly executed
9 under the law of the State in which it is presented.

10 “(B) In the absence of knowledge to the contrary,
11 a physician or other health care provider or organization
12 may presume that a written advance health care directive
13 or similar instrument, regardless of where executed, is
14 valid.

15 “(C) In the absence of a validly executed advance di-
16 rective, any authentic expression of a person’s wishes with
17 respect to health care shall be honored.

18 “(D) The provisions of this paragraph shall preempt
19 any State law on advance directive portability to the extent
20 such law is inconsistent with such provisions. Nothing in
21 the paragraph shall be construed to authorize the adminis-
22 tration of health care treatment otherwise prohibited by
23 the laws of the State in which the directive is presented.”.

24 (b) GAO STUDY ON HEALTH CARE DECISIONMAKING
25 LAWS AND BARRIERS TO THE USE OF ADVANCE DIREC-
26 TIVES.—

1 (1) STUDY.—The Comptroller General of the
2 United States shall conduct a study that examines
3 the use, portability, and electronic storage of ad-
4 vance directives and that identifies barriers towards
5 adopting, using, and following advance directives in
6 the clinical setting. Such examination shall include
7 issues that remain unresolved after the Stage 3
8 Meaningful Use final rule, including barriers and so-
9 lutions to finding and accessing advance care plan-
10 ning documents, best practices for alerting eligible
11 providers to the presence of an advance care plan,
12 and best practices for transmitting advance care
13 plans across sites of care.

14 (2) REPORT.—Not later than 1 year after the
15 date of the enactment of this Act, the Comptroller
16 General shall submit to Congress a report on the
17 study conducted under paragraph (1) and shall in-
18 clude in the report such recommendations regarding
19 improving advance health care planning as the
20 Comptroller General deems appropriate.

21 **SEC. 6. APPLICATION OF QUALITY MEASURES UNDER**
22 **MEDICARE RELATING TO END-OF-LIFE CARE.**

23 (a) INCORPORATING END-OF-LIFE CARE SUB-
24 DOMAINS WITHIN QUALITY DOMAINS UNDER MEDICARE
25 PHYSICIAN FEE SCHEDULE.—Section 1848(s)(1) of the

1 Social Security Act (42 U.S.C. 1395w-4(s)(1)) is amend-
2 ed by adding at the end the following new subparagraph:

3 “(G) END-OF-LIFE SUBDOMAINS RELATING
4 TO QUALITY DOMAINS.—Within one or more ap-
5 propriate quality domains, the Secretary shall
6 establish subdomains relating to end-of-life
7 care, including subdomains relating to each of
8 the following:

9 “(i) The process of eliciting and docu-
10 menting goals, preferences, and values of
11 the patient (and, where relevant and ap-
12 propriate, family caregiver) regarding end-
13 of-life care from the patient or from a le-
14 gally authorized representative, including
15 the articulation of goals that accurately re-
16 flect how the patient wants to live.

17 “(ii) The effectiveness, patient-cen-
18 teredness (and, where relevant, family
19 caregiver-centeredness), and accuracy of
20 end-of-life care plans, including docu-
21 mentation of individual goals, preferences,
22 and values.

23 “(iii) Agreement and consistency with
24 respect to end-of-life care among—

1 “(I) patient’s goals, values, and
2 preferences;

3 “(II) any documented care plan;
4 and

5 “(III) the care delivered.”.

6 (b) INCORPORATING QUALITY MEASURES ON END-
7 OF-LIFE CARE FOR POST-ACUTE CARE (PAC).—Section
8 1899B of the Social Security Act (42 U.S.C. 1395lll) is
9 amended—

10 (1) in subsection (a)(2)(E)(i)—

11 (A) by striking “and” at the end of sub-
12 clause (IV);

13 (B) by striking the period at the end of
14 subclause (V) and inserting “; and”; and

15 (C) by adding at the end the following new
16 subclause:

17 “(VI) with respect to the domain
18 described in subsection (c)(1)(F) (re-
19 lating to end-of-life care)—

20 “(aa) for PAC providers de-
21 scribed in clauses (ii), (iii), and
22 (iv) of paragraph (2)(A), October
23 1, 2018; and

24 “(bb) for PAC providers de-
25 scribed in clauses (i) of such

1 paragraph, January 1, 2019.”;

2 and

3 (2) in subsection (c)(1), by adding at the end
4 the following new subparagraph:

5 “(F) The effectiveness, patient-centered-
6 ness (and, where relevant, family caregiver-cen-
7 teredness), and accuracy of end-of-life care
8 plans and communications relating to such
9 plans, including—

10 “(i) documentation of a patient’s
11 goals, preferences, and values; and

12 “(ii) agreement and consistency with
13 respect to end-of-life care among—

14 “(I) patient’s goals, values, and
15 preferences;

16 “(II) any documented care plan;
17 and

18 “(III) the care delivered.”.

19 **SEC. 7. ANNUAL REPORT ON MEDICARE DECEDENTS.**

20 The Secretary of Health and Human Services shall
21 issue for each fiscal year (beginning no later than fiscal
22 year 2018) an annual report that analyzes the cir-
23 cumstances of Medicare beneficiaries who died during the
24 fiscal year covered by such report. Such analysis shall in-
25 clude at least the following with respect to such decedents:

1 (1) Information on the care or payor settings
2 (such as under part A or part C of Medicare) at the
3 time of death.

4 (2) Information on the demographic character-
5 istics of such decedents.

6 (3) Information on the geographic distribution
7 of such decedents.

8 (4) An evaluation of the Medicare claims data
9 for such decedents for services furnished in the last
10 year of life, including an analysis of the setting of
11 care for decedents who had more than one chronic
12 illness at the time of death.

13 (5) Such other information as the Secretary
14 deems appropriate.

15 **SEC. 8. GRANTS TO INCREASE PUBLIC AWARENESS OF AD-**
16 **VANCE CARE PLANNING.**

17 (a) IN GENERAL.—The Secretary of Health and
18 Human Services shall award grants to increase public
19 awareness of advance care planning. Such grants shall be
20 awarded under such terms and conditions as the Secretary
21 shall specify.

22 (b) TYPES OF GRANTS.—Grants under this section
23 may provide for the development of—

24 (1) decision support tools and instructional ma-
25 terials for individuals, family caregivers, and health

1 care providers that include the importance of plan-
2 ning for treatment decisions, discussing values and
3 goals related to catastrophic injury or illness, and
4 completing an advance directive; and

5 (2) materials for individuals that presents the
6 importance of articulating goals of care, under-
7 standing disease diagnosis and prognosis, evaluating
8 treatment options, and developing a plan of care,
9 and documenting the treatment plan.

10 (c) AUTHORIZATION OF APPROPRIATIONS.—There
11 are authorized to be appropriated to carry out this section
12 for the 5-fiscal-year period beginning with fiscal year 2017
13 \$20,000,000, to remain available until expended.

14 **SEC. 9. ADVANCE CARE PLANNING AND PALLIATIVE CARE**
15 **EDUCATION AND TRAINING.**

16 (a) IN GENERAL.—The Secretary of Health and
17 Human Services shall award grants to eligible entities to
18 develop and implement programs and initiatives to train
19 and educate individuals to provide advance care planning,
20 advance illness care, hospice care, and palliative care in
21 hospital, hospice, home, community, and long-term care
22 settings.

23 (b) ELIGIBLE ENTITIES.—For purposes of this sec-
24 tion, eligible entities may be a medical school, a nursing

1 school, a health care system, non-profit organization, or
2 other entity the Secretary deems appropriate.

3 (c) USE OF FUNDS.—Funding under grants awarded
4 under this section shall be used—

5 (1) to provide training and continuing edu-
6 cation to individuals who will provide advance care
7 planning services or palliative care in the hospital,
8 hospice, home, community, and long-term care set-
9 tings; and

10 (2) to develop curricula or teaching materials
11 related to advance care planning or palliative care in
12 such settings.

13 (d) AUTHORIZATION OF APPROPRIATIONS.—There
14 are authorized to be appropriated to carry out this section
15 for the 5-fiscal-year period beginning with fiscal year 2017
16 \$20,000,000, to remain available until expended.

17 **SEC. 10. ADVANCE CARE PLANNING ADVISORY COUNCIL.**

18 (a) ESTABLISHMENT.—Not later than 180 days after
19 the date of the enactment of this Act, the Secretary of
20 Health and Human Services (in this section referred to
21 as the “Secretary”) shall establish within the Office of the
22 Secretary an advisory committee to be known as the Ad-
23 vance Care Planning Advisory Council (in this section re-
24 ferred to as the “Council”).

25 (b) DUTIES.—

1 (1) MISSION.—The Council shall advise the
2 Secretary regarding the compilation, development,
3 and dissemination of resources for individuals facing
4 advanced and terminal illness.

5 (2) RESPONSIBILITIES.—Responsibilities of the
6 council include the following:

7 (A) Ensuring that resources provided con-
8 tain non-biased information about the range of
9 options available to individuals with advance
10 and terminal illness, including information
11 about conventional, curative treatments, pallia-
12 tive care, and hospice care.

13 (B) Developing strategies for increasing
14 public understanding about advanced illness
15 and the important role advance care planning
16 can play in documenting an individual's wishes
17 for medical care for loved ones in the event that
18 individual cannot communicate the individual's
19 his or her wishes.

20 (C) Compiling information for dissemina-
21 tion regarding existing advance care planning
22 models including POLST, MOLST, advance di-
23 rectives, and healthcare proxies.

24 (D) Promoting interagency coordination
25 and minimizing overlap regarding advance care

1 planning, including opportunities to coordinate
2 efforts between the Federal agencies and exter-
3 nal stakeholders.

4 (E) Identifying and evaluating cross-cut-
5 ting issues such as perinatal end-of-life care
6 and advance care planning access issues.

7 (c) MEMBERSHIP.—

8 (1) IN GENERAL.—The Council shall be com-
9 posed of up to 15 members appointed by the Sec-
10 retary from among qualified individuals who are not
11 officers or employees of the Federal Government.

12 (2) GROUPS.—The members of the Council
13 shall include the following:

14 (A) At least 3 members with clinical train-
15 ing and an expertise in advanced illness or end-
16 of-life care.

17 (B) At least 3 members from patient and
18 family advocacy groups.

19 (C) At least 3 members from religious or
20 spiritual organizations.

21 (D) Other members from interested stake-
22 holder groups with a proven expertise in chron-
23 ic, advanced, and end-of-life care.

1 (d) APPLICABILITY OF FACA.—The Council shall be
2 treated as an advisory committee subject to the Federal
3 Advisory Committee Act (5 U.S.C. App.).

○