

Federal Bills Addressing Advanced Illness, Advance Care Planning, and Family Caregiving

115th Congress, 2018 (as of March 9, 2018)

Legislation	Sponsors	Summary
<p>1 CHRONIC care Act of 2017 (“Creating High-Quality Results and Outcomes Necessary to Improve Chronic Care”)</p>	<p>Enacted 2/9/18 as part of the Bipartisan Budget Act of 2018, Public Law No. 115-123 (H.R.1892)</p> <p>Was introduced as: S. 870, Sen. Hatch (R-UT) (4/6/2017) <i>21 cosponsors</i></p>	<ul style="list-style-type: none"> • Extends the Independence at Home demonstration program for 2 more years and increase the number of patients covered to 15,000. • Modifies provisions regarding access to home dialysis therapy to incorporate telehealth technologies; • Permanently authorizes SNPs (Special Needs Plans) if certain additional policy requirements are met. Rather than expiring under current law on December 31, 2018, SNPs could continue to enroll qualifying Medicare beneficiaries so long as they adopt the requirements outlined in the bill • Expands testing of the MA Value-Based Insurance Design test model to allow an MA plan in any state to participate in the model by 2020, and permits continuation beyond 2022 under certain conditions; • Allows an MA plan to offer a wider array of supplemental benefits to chronically ill enrollees beginning in 2020. These benefits would be defined as those that have a reasonable expectation of improving or maintaining the health or overall function of the chronically ill enrollee and would not be limited to primarily health-related services. • Allows MA plans and ACOs to provide additional telehealth benefits to enrollees and, to chronically ill enrollees; • Expands the use of telehealth services for stroke by eliminating the originating site geographic restrictions for telehealth services; • Allows prospective, voluntary assignment of Medicare fee-for-service beneficiaries to accountable care organizations (ACOs); and • Allows ACOs to operate beneficiary incentive programs to encourage beneficiaries to obtain medically necessary primary care services • Requires the Government Accountability Office to conduct studies on: (1) the establishment of a payment code for a visit for longitudinal comprehensive care planning services; (2) improving Medication Synchronization; and (3) the impact of obesity drugs on patient health and spending.

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<p>2 RAISE Family Caregivers Act (“Recognize, Assist, Include, Support, and Engage” Family Caregivers Act)</p>	<p>Enacted 1/22/18 as Public Law No: 115-119</p> <p>S. 1028, Sen. Collins (R-ME), Sen. Baldwin (D-WI), Sen. Ayotte (R-NH), Sen. Bennet (D-CO), Sen. Mikulski (D-MD) (5/03/17) <i>15 cosponsors</i></p> <p>H.R. 3759, Gregg Harper (R-MS) (9/13/17) <i>113 cosponsors</i></p>	<p>Directs the Department of Health and Human Services (HHS) to develop, maintain, and keep updated a National Family Caregiving Strategy and to convene a Family Caregiving Advisory Council to advise on recognizing and supporting family caregivers (sunsets in 5 years).</p>
<p>3 Palliative Care and Hospice Education and Training Act</p>	<p>S. 693, Sen. Baldwin (D-WI) (3/22/2017) <i>29 cosponsors</i></p> <p>H.R. 1676, Rep. Engel (D-NY), Rep. Reed (R-NY), Rep Rep. Carter (R-GA) (3/22/2017) <i>258 cosponsors</i></p>	<ul style="list-style-type: none"> Amends the Public Health Service Act to provide support for Palliative Care and Hospice Education Centers and to increase the number of permanent faculty in palliative care at accredited allopathic and osteopathic medical schools, nursing schools, social work schools, and other programs, including physician assistant education programs, to promote education and research in palliative care and hospice, and to support the development of faculty careers in academic palliative medicine. Requires the Agency for Healthcare Research and Quality to provide for a national education and awareness campaign to inform patients, families, and health professionals about the benefits of palliative care. Requires NIH to expand national research programs in palliative care.
<p>4 Patient Choice and Quality Care Act of 2017</p>	<p>S. 1334 Sen. Warner (D-VA), Sen. Isakson (R-GA), Sen. Baldwin (D-WI), Sen. Capito (R-WV), Sen. Collins (R-ME), Sen. Klobuchar (D-MN) (6/12/2017) <i>7 cosponsors</i></p>	<ul style="list-style-type: none"> Directs CMS to create and test a new advanced illness care and management model—offered both independently and in conjunction with other models—that would enable eligible individuals with a serious, chronic progressive or advanced illness to voluntarily engage in a team-based planning process designed to align the care a patient receives with his or her goals of care, values, and preferences.

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	<p>H.R. 2797 Rep. Blumenauer (D-OR), Rep. Roe (R-TN) (6/9/2017) <i>24 cosponsors</i></p>	<ul style="list-style-type: none"> • Facilitates the development of quality measures for advance care planning; • Expands coverage of advance care planning services to include trained social workers. • Directs HHS to include information in the Medicare & You Handbook about advance directives, planning services, planning tools, and portable treatment orders. • Requires HHS to develop standards for including completed advance care planning documents within a patient’s electronic health record. • Enhances the recognition of out-of-state advance directive. • Strengthens the documentation of advance directives and portable treatment orders by hospitals, skilled nursing facilities, home health agencies, and hospice programs and upon discharge, requires them to send documentation to the individual’s primary care provider and any facility to which the individual is transferred; • Authorizes grants to improve public awareness of advance care planning and to develop, expand, and provide a national support center for POLST programs. • Establishes an Advisory Council to advise the Secretary on issues of advanced and terminal illness. • Requires the Secretary to issue an annual report of death data.
<p>5 Medicare Choices Empowerment and Protection Act</p>	<p>S. 1530, Sen. Coons (D-DE), Sen. Cassidy (R-LA), Sen. Barrasso (R-WY), Sen. Bennet (D-CO) (7/11/2017) <i>3 cosponsors</i></p> <p>H.R. 3181, Rep. Black (R-TN), Rep. Welch (D-VT), Rep. Thompson (D-CA), Rep. Collins (R-NY) (7/11/2017) <i>3 cosponsors</i></p>	<ul style="list-style-type: none"> • Would allow for a one time financial incentive of \$75 to Medicare beneficiaries to complete an advance directive and register it with an online advance directive registry accredited by the Secretary. • Also provides for information in the Medicare and You Handbook on the importance of advance directives.
<p>6 Independence at Home Act</p>	<p>S. 464, Sen. Markey (D-MA), Sen. Cornyn (R-TX), Sen. Bennet (D-CO), Sen. Portman (R-OH) (2/28/2017)</p>	<p>Establishes a permanent Independence at Home Medical Practice Program, under which a primary care practice shall be accountable for providing comprehensive, coordinated, continuous, and accessible care to applicable chronically ill Medicare beneficiaries at home, and coordinating health care across all treatment settings.</p>

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<p>7 Disability Integration Act of 2017</p>	<p>S. 910, Sen. Schumer (D-NY), Sen. Casey (D-PA), Sen. Warren (D-MA) (4/7/2017) <i>17 cosponsors</i></p> <p>H.R. 2472, Rep. Sensenbrenner (R-WI) (5/16/2017) <i>83 cosponsors</i></p>	<ul style="list-style-type: none"> • Prohibits states or local governments that provide institutional placements for individuals with disabilities who need long-term assistance with ADLs or health-related tasks and insurance providers that fund such long-term services from denying community-based services that would enable such individuals to live in the community and lead an independent life. • Prohibits States, local governments, or insurance providers from discriminating against such individuals in the provision of community-based services by: (1) imposing prohibited eligibility criteria, cost caps, waiting lists, or payment structures; (2) failing to provide a specific community-based service; or (3) requiring an individual to receive a service in a congregate or disability-specific setting. • Requires community-based services to be offered to individuals with such disabilities prior to institutionalization. Institutionalized individuals must be notified regularly of community-based alternatives. • Requires States, local governments, and public insurance providers to assess: (1) transportation barriers that prevent individuals from receiving services in integrated settings, and (2) the availability of integrated employment opportunities. • DOJ and HHS must issue regulations accordingly. • State and local governments, in conjunction with housing agencies, must ensure sufficient availability of affordable, accessible, and integrated housing that is not a disability-specific residential setting or a setting where services are tied to tenancy. • Regulations must require states and local governments to begin implementing a transition plan to achieve the requirements of the bill within 12 years after enactment. For 10 years after issuance of the regulations, HHS must determine annually whether each state is complying with the transition plan. If a state is complying, HHS must increase the State’s FMAP by 5 percentage points for states requesting an increase for expenditures on home and community-based services furnished under the state Medicaid plan, or a waiver of such plan, that are identified as: (1) improvements to ensure accessibility or self-directed

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		<p>receipt of such services, (2) funding shifts from institutional settings to integrated community-based services, or (3) environmental modifications for housing targeted toward the lowest income individuals.</p> <ul style="list-style-type: none"> • The bill provides for DOJ enforcement and allows civil actions by individuals subjected to, or about to be subjected to, a violation of this bill.
<p>8 Compassionate Freedom of Choice Act of 2017</p>	<p>H.R. 1020, Rep. Morgan (R-VA) & Rep. Dave (R-VA) (2/13/2017) <i>1 cosponsor</i></p>	<ul style="list-style-type: none"> • Amends the Federal Food, Drug, and Cosmetic Act to prevent the FDA from preventing or restricting the manufacture, importation, distribution, or sale of drugs or medical devices that are (1) intended for terminally ill patients, (2) have been the subject of one or more clinical trials, and (3) have not been approved by the FDA. • The FDA may not require the disclosure, collection, or reporting of certain information concerning such drugs or devices. • Except in the case of gross negligence or willful misconduct, a person who manufactures, imports, distributes, prescribes, or administers such a drug or device is not liable under state or federal law for loss, damage, or injury from the development, testing, production, acquisition, use, safety, or effectiveness of the drug or device.
<p>9 FAMILY Act (Family and Medical Insurance Leave Act)</p>	<p>S. 337, Sen. Gillibrand (D-NY) (2/07/2017) <i>32 cosponsors</i></p> <p>H.R. 947, Rep. DeLauro (D-CT) + 112 original cosponsors (2/07/2017) <i>154 Cosponsors</i></p>	<ul style="list-style-type: none"> • Establishes the Office of Paid Family and Medical Leave within the SSA. • Entitles every individual to a family and medical leave insurance (FMLI) benefit payment for each month beginning on the 1st day of the month in which the individual meets the criteria specified below and ending 365 days later (benefit period), not to exceed 60 qualified caregiving days per period. • An individual qualifies for such a benefit payment if such individual: <ul style="list-style-type: none"> ○ Is insured for disability insurance benefits under the SSSA at the time an application is filed; ○ Has earned income from employment during the 12 months before filing; and ○ Was engaged in qualified caregiving (any activity for which the individual would be entitled to leave under the Family and Medical Leave Act of 1993), or anticipates being so engaged, during the 90-day period before the application is filed or within 30 days after. • Prescribes a formula for determination of an individual's monthly benefit, with maximum and minimum amounts.

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		<ul style="list-style-type: none"> Benefit to be coordinated with any periodic benefits received under a state or local temporary disability insurance or family leave program. <p>The bill prescribes criteria that make an individual ineligible for an FMLI benefit payment and specifies prohibited acts by an employer and penalties for violations.</p> <p>The bill establishes the Federal Family and Medical Leave Insurance Trust Fund. FMLI benefit payments shall be made only from this fund.</p> <p>No amounts from the Social Security Trust Funds or appropriated to the SSA to administer Social Security programs may be used for FMLI benefits or administration.</p> <p>The bill amends the Internal Revenue Code to impose a tax on every individual and employer, all self-employment income, and every railroad employee, employee representative, or railroad employer to finance the Federal Family and Medical Leave Insurance Trust Fund for FMLI benefits.</p>
10 Protecting Life Until Natural Death Act	H.R. 410 , Rep King (R-IA) (1/10/2017) <i>0 cosponsors</i>	<ul style="list-style-type: none"> Excludes ACP services from Medicare coverage (except hospice services).