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March 13, 2020

Senate Finance Committee Subcommittee on Health Care

RE: Senate Finance Subcommittee on Health Care Seeks Feedback on Actions to
Address Alzheimer's Disease

Submitted to: ALZFeedback@toomey.senate.gov

Dear Senators Toomey and Stabenow,

The National Coalition for Hospice and Palliative Care is pleased to submit feedback in response to your request for information from stakeholders for suggested policy solutions to improve Alzheimer's care in the nation.

Introduction and Background

The National Coalition for Hospice and Palliative Care (Coalition) represents the 12 leading professional organizations dedicated to advancing the delivery of high-quality serious illness care to all who need it. The national organizations that form the Coalition represent more than 5,200 physicians, 1,000 physician assistants, 11,000 nurses, 5,000 chaplains, 8,000 social workers, researchers, and pharmacists, along with over 1,800 palliative care programs and 5,300 hospice programs and their related personnel, caring for millions of patients and families each year across the United States. Millions of the patients and families we care for suffer from Alzheimer's disease and related dementias. As such, we bring a broad, interdisciplinary perspective to this request from the Senate Finance Committee.

We are providing both feedback and potential legislative and regulatory policy solutions to improve the care and quality of life for patients and families with Alzheimer's – many of whom our members serve every day. Our Coalition firmly believes that, through increased access to care planning services, palliative care and hospice, the quality of life for patients and families with Alzheimer's will improve. Specific policy recommendations are included below in response to the Committees specific topic areas.

Increasing the Use of Palliative Care

The Coalition has included a detailed description of palliative care in this Request for Information (RFI) because we believe that palliative care can provide significant support to patients facing Alzheimer's disease and their families. Given the long duration of the disease (patients age 65 years and older survive an average of 4 to 8 years following diagnosis), and the changing support needs experienced by patients

and caregivers over time, the palliative care provider can adjust the care plan for the patient and their family accordingly.

1. Definition of Palliative Care

The Centers for Medicare & Medicaid Services (CMS) defines palliative care as: “patient- and family- centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.” The definition is referenced in the CMS Medicare Hospice Conditions of Participation.¹

The Coalition recognizes that the practice of palliative care has expanded into all care settings and therefore expands the CMS definition of palliative care in the following way: “Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.”²

2. Stages: The delivery of palliative care for the Alzheimer’s patient is often broken out into three stages:

- A. Early Stage.** Upon diagnosis, the palliative care team provides support by discussing the disease with the patient and family, particularly regarding what to expect; discussing the patient's values and care preferences given the reality of the diagnosis, collaboratively determining appropriate goals of care and then developing a comprehensive care plan based on those goals; detecting and treating physical and behavioral symptoms; helping the patient and family anticipate some of the more administrative aspects of care (e.g., appointing a health care proxy; financial planning, etc.); and providing the family with education and support resources. This is done in partnership with the patient’s treating provider, and the palliative care team is able to provide an extra layer of support for everyone. It is at this stage in the disease process that advance care planning is often discussed, while the patient is still able to communicate their wishes.
- B. Middle Stage.** During this stage, the patient’s memory loss, confusion, and agitation become more prominent, and they require increasing support and supervision from caregivers. The palliative care team encourages the patient and family to complete important tasks and helps the family/caregivers prepare for increasing personal care needs and associated out-of-pocket healthcare costs. The palliative care team also comprehensively assesses the patient to identify all potential sources of suffering (i.e., physical symptoms due to the disease and/or other conditions, as well as social, psychological, and spiritual concerns), and provides person-centered care to address any issues. The team reviews goals of care periodically and recommends any appropriate changes to the care plan.
- C. Late Stage.** During this stage, the patient becomes fully dependent, including losing the ability to walk, sit up, swallow, and speak. Symptoms may include unawareness of the time and place, difficulty recognizing relatives and friends, needing help with self-care, and behavior changes that

¹ Hospice Conditions of Participation Final Rule; 2008: <https://www.govinfo.gov/content/pkg/FR-2008-06-05/pdf/08-1305.pdf>

² Clinical Practice Guidelines for Quality Palliative Care: 2018: https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf

may escalate and include aggression. The palliative care team recommends hospice if the prognosis is 6 months or less based on the patient's function, other serious illnesses, and complications, such as weight loss, infections, severe behavioral problems, skin ulcers and hospitalizations. At this stage in the disease process, the hospice team would provide symptom management support to the patient and ongoing psychosocial and spiritual support to the family and loved ones. If the patient is a nursing home resident, the hospice would also provide support and counseling to the nursing facility residents and staff.

If the patient is ineligible or declines hospice, the palliative care team can help the family explicitly plan for a peaceful death and encourage completion of important tasks such as saying goodbye.

- 3. Comprehensive assessment and establishing goals of care:** Regardless of stage, palliative care teams provide comprehensive assessment to clarify the goals of care for all patients with dementia:
 - Reviewing the patient and family's understanding of prognosis.
 - Discussing diagnosis, prognosis, and what to expect in the future with both patient and family.
 - Assessing physical and psychological symptoms and function.
 - Assessing social, spiritual and cultural needs.
 - Reviewing patient preferences and determining surrogate decision-makers.
 - Assessing caregiver needs and capacity.
 - Discussing the financial implications of progressive intensive personal care needs.
 - Reviewing efficacy and benefit-to-burden ratio for treatments of comorbid diseases, with a focus on relieving the suffering that the patient may not be able to communicate.
 - Recommending appropriate changes to the care plan based on patient and family priorities.

- 4. Focus on the patient for care and caregiver support:** All of this is done with the lens of maximizing patient and family quality of life throughout the course of the illness. Particularly in the instance of Alzheimer's disease, the palliative care team must focus as much on the family/caregiver as the patient. Caregivers of cognitively impaired people assist with daily activities over many years, and the success of any care plan is dependent upon the caregiver's well-being. Yet fewer than half of caregivers for people with dementia receive counseling or other support, and only about a quarter report a clinician ever asking them about their own self-care needs.³ Caregivers also have a much higher risk of getting sick themselves, with the additional strain often resulting in increased utilization of hospital services and ED visits as their health deteriorates over the caregiving period.⁴ The palliative care team is specially-trained to support caregivers by comprehensively assessing caregiver readiness, providing counseling and support, educating them on what to expect, providing training and skill building (including how to understand and respond to behavioral symptoms of dementia), coordinating care, and providing referrals to community-based organizations.

- 5. Primary goal of palliative care:** While the primary goal of palliative care is to improve quality of life for patients with serious illness and their families by proactively addressing symptoms, improving communication, and supporting caregivers, there is also evidence that it decreases unnecessary or

³ Belmin, J., Min, L., Roth, C., Reuben, D., Wenger, N. "Assessment and Management of Patients with Cognitive Impairment and Dementia in Primary Care," *J Nutr Health Aging*, 2012; 16(5): 462-7 & National Alliance for Caregiving. *Dementia Caregiving in the U.S.: National Alliance for Caregiving and Alzheimer's Association*. February 2017. Web Access: http://www.caregiving.org/wp-content/uploads/2017/02/DementiaCaregivingFINAL_WEB.pdf

⁴ Schulz, R., Cook, T. *Caregiving Costs: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient*. National Alliance for Caregiving; Bethesda, Maryland, 2011; 7p

unwanted hospitalizations and medical interventions.^{5,6} Yet, despite the value of palliative care throughout the trajectory of Alzheimer’s disease, the healthcare system is not designed to support the kind of longitudinal, interdisciplinary care that palliative care delivers.

6. Key cross-cutting challenges for care of people with dementia

The Coalition has identified a number of cross-cutting challenges for the care of people with Alzheimer’s disease and related dementias. The topics listed below will be discussed in detail in relevant sections of this response to the RFI.

- Inadequate diagnosis and functional assessment.
- Inadequate clinician training.
- Frequent and problematic care transitions triggered by payment policies rather than patient needs.
- Patient/caregiver burdens related to transport and limited access to specialty-level palliative care.
- Lack of meaningful, cross-cutting quality measures.

1. Care Coordination in Federal Health Care Programs:

Dually Eligible Beneficiaries: The subcommittee seeks input on how best to increase care coordination efforts for individuals with Alzheimer’s and related dementias in federally- funded programs that care for dual eligible beneficiaries, such as the Programs of All- Inclusive Care for the Elderly (PACE), Medicare Fee-for-Service, Medicaid, and under the Financial Alignment duals demonstrations. Additionally, we are seeking feedback on successes, challenges, and opportunities to improve the quality of care these programs provide.

Dually Eligible Beneficiaries:

Our Coalition members find that patients with Alzheimer’s and related dementias under their care routinely transition back and forth across settings. This is often because the medical care, personal care, and family support needs that would enable patients to stay safely at home are often not covered by Medicare, Medicaid, or commercial health plans or that payment policies dictate the care that is available or delivered, rather than focused on the patient’s needs.

1. The nursing home resident with Alzheimer’s disease:

- The SNF skilled benefit will pay for nursing home care for a specified number of days. However, the SNF skilled benefit and the Medicare Hospice Benefit cannot be provided concurrently, so most families don’t select hospice even when the patient is eligible. The cost of nursing home care is so astronomical (normally thousands of dollars per month) that the family has no choice financially.

⁵ May, P, MM Garrido, JB Cassel, et al. “Cost Analysis of a Prospective Multi-site Cohort Study of Palliative Care Consultation Teams for Adults with Advanced Cancer: Where Do Cost Savings Come From?” *J Palliat Med*, (2017) & Adelson, K, J Paris, JR Horton, et al. “Standardized Criteria for Palliative Care Consultation on a Solid Tumor Oncology Service Reduces Downstream Health Care Use.” *J Oncol Pract*, (2017): 13(5); & Triplett D et al: Effect of Palliative Care on Aggressiveness of End-of-Life Care Among Patients With Advanced Cancer. *J Onc Prac* 2017; 13:e760-e767

⁶ O’Connor N, Moyer M, Behta M, Casarett D: The Impact of Inpatient Palliative Care Consultations on 30-Day Hospital Readmissions. *J Palliat Med* 2015; 18: 956-961.

- The nursing home has financial incentives to place the patient on the Medicare SNF benefit as the rates are significantly higher than the rate the hospice pays for nursing home room and board for the dually eligible patient.
- These financial incentives driving preferential utilization of the Medicare SNF benefit are compounded when Medicaid rates for long term care room and board are low. Proposals that would negatively impact state Medicaid funding, such as the Medicaid Fiscal Accountability Proposed Rule, would only exacerbate the problem.

Recommendations: We urge the protection and enhancement of federal Medicaid funding so that care aligns with patient needs rather than the challenges of payment policy.

In addition, CMS should allow the terminally ill patient to elect their Medicare Hospice Benefit concurrently with the SNF skilled benefit, if eligible, without financial penalties to the patient and family, so that the nursing home resident can receive hospice care.

2. Misinterpretation of Medicaid policy for hospice-eligible patients related to home and community-based services (HCBS):

Within broad Federal guidelines, states are permitted to develop home and community-based services waivers (HCBS waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting. For many individuals living with Alzheimer's and other dementias, staying at their home in familiar surroundings is key to their continued care and quality of life. Nearly all states and DC offer services through HCBS waivers.

State HCBS Waiver programs must:

- Demonstrate that providing waiver services won't cost more than providing these services in an institution
- Ensure the protection of people's health and welfare
- Provide adequate and reasonable provider standards to meet the needs of the target population
- Ensure that services follow an individualized and person-centered plan of care

Under the HCBS waiver program, Medicaid-eligible beneficiaries receive personal care and other assistance because HCBS are meant to prevent patients (including those living with dementia) from having to relocate to a nursing home prematurely due to the progression of the disease. The issue often encountered with dually eligible patients receiving HCBS who are terminally ill and want to utilize hospice services is that the Medicaid case managers often misapply the rule. The regulation⁷ allows for the Medicare Hospice Benefit services to be provided to beneficiaries simultaneously with Medicaid HCBS, provided there is no duplication of service (nothing Medicare covers can be covered by Medicaid). The regulations allow the HCBS case manager to ensure that only those services not duplicated under Medicare are provided. Providers often find that case managers and sometimes the State Medicaid offices do not understand these coverage requirements and convey that these two levels of services

⁷ HCBS Final rule; 2014: <https://www.govinfo.gov/content/pkg/FR-2014-01-16/pdf/2014-00487.pdf>

(Medicare Hospice Benefit and Medicaid HCBS) cannot be provided simultaneously, requiring the patient to choose one over the other. When the patient and their caregivers must choose, they almost always choose the HCBS hours over the Medicare Hospice Benefit, as HCBS allows the patient to remain in the home and provides support to the caregiver.

Example: A terminally ill individual may have a caregiver who is a teacher. HCBS hours were provided from 7 AM to 3 PM Monday through Friday to allow the caregiver to work during the school year. These hours were drastically reduced during the summer vacation months. When the patient was referred to and wanted to elect hospice care, the HCBS case manager said the patient could receive HCBS hours or hospice but not both, because hospice is supposed to cover all of the patient's needs and should be providing all of the hours HCBS was providing. This is not accurate, as Medicare NEVER covers hours intended to keep the patient in his/her home and out of an institution. The hospice should determine what was needed as part of the hospice plan of care and provide those hours, while HCBS continues to provide the rest of the needed hours so that care coordination occurs, and the patient receives the necessary supports to remain at home.

Recommendation: Congress should direct CMS to issue clarifying guidance to state Medicaid offices clearly specifying that patients receiving HCBS should not be required to drop HCBS in order to access hospice services. State Medicaid offices should encourage the HCBS program to provide the necessary care coordination for terminally ill patients to ensure that both HCBS and hospice services can be provided, that there is no overlap in services, and that the patient may remain in the community.

- **Medicare Advantage Benefits:** Patients with Alzheimer’s have unique needs, requiring a comprehensive set of benefits to improve the quality of care. Medicare Advantage plans have recently been authorized to offer supplemental services, such as transportation, adult day care, meal delivery, and home- and community-based services. The subcommittee is interested in understanding how these services have impacted Alzheimer’s patients and exploring challenges and opportunities to further serve these beneficiaries. The subcommittee also seeks feedback on what the traditional Medicare program should cover in order to better serve individuals with Alzheimer’s.

For purposes of these comments, we are including recommendations to strengthen MA contractual requirements.

Medicare Advantage (MA) plans have significant opportunities to offer supplemental services to beneficiaries, including patients with Alzheimer’s and other dementias. We note that, in the description of supplemental benefits, there is little guidance provided to MA plans around “community-based palliative care” except that eligibility is for patients with a life expectancy greater than 6 months. Since 2004, the Coalition has developed guidelines for quality palliative care that are publicly available. The most recent 4th edition, [National Consensus Project Clinical Practice Guidelines for Quality Palliative Care](#), was published in 2018 by a team of leading palliative care professionals and endorsed by ninety-three professional organizations. These clinical practice guidelines could be used as a reference for MA plans seeking to offer community-based palliative care for their beneficiaries to define services and benefits.

Recommendations: Medicare Advantage plans should have standardized operations that enable early identification and intervention for their enrollees with Alzheimer’s and other dementias. Therefore, the Coalition is pleased to recommend the following for MA plan of care submission requirements.

1. Early identification of enrollees with Alzheimer’s or other dementia: Every MA plan should have a process in place to identify enrollees with symptoms of dementia, such as through a Health Risk Assessment or network screening initiative.
2. Care management expanded assessment: Every MA plan’s case managers should be training in basic symptom and functional assessment as well as basic communication skills needed when working with seriously ill patients and their families.
3. Home-based primary and palliative care: Every MA plan should have a program or benefit in place to provide home-based primary and palliative care for those enrollees with serious illness; in this case, additional eligibility criteria may be applied under special supplemental benefits.
4. Network Adequacy and Oversight:
 - a. Every MA plan should have an identified list of palliative care specialists and programs in their network.
 - b. Every network hospital should have access to an interdisciplinary palliative care team and has a process to identify patients in need of palliative care consultation.
 - c. Every network hospital should have a training program for all relevant staff, which: enhances understanding of palliative care, its benefits, and who needs it; basic communication skills needed when working with seriously ill patients and their families; and basic pain/symptom assessment and management skills.
 - d. Every network SNF should have a training program for all relevant staff, covering the topics above.
5. Risk Adjustment: To ensure sufficient management of enrollees with dementia, the risk-adjustment calculations based on Hierarchical Condition Categories (HCCs) should weight dementia diagnoses more heavily.

- **Special Needs Plans (SNPs): SNPs have recently been permanently authorized and are afforded considerable flexibilities to better coordinate care for more complex populations with chronic care needs. We are seeking feedback as to how these plans manage care for enrollees with Alzheimer’s disease compared to traditional Medicare Advantage plans and if additional flexibility is needed to improve care coordination and quality.**

All Coalition recommendations listed above for Medicare Advantage plans apply to MA Special Needs Plans.

- **Medicare Coverage of Care Planning Services: Dementia-specific care planning can lead to fewer hospitalizations, fewer emergency room visits, and better medication management. In 2017, CMS implemented a new Medicare benefit (CPT code 99483) based on the bipartisan HOPE for Alzheimer’s Act. Uptake of the code has been slow. We are seeking feedback on how to improve access to comprehensive care planning services for individuals with Alzheimer’s and related dementias.**

The need for timely, comprehensive care planning for patients diagnosed with Alzheimer’s disease was recognized by members of the Senate Finance Committee and others who incorporated into the “HOPE for Alzheimer’s Act” a requirement that Medicare cover comprehensive care planning services provided to beneficiaries and their caregivers following a diagnosis of Alzheimer’s disease, as well as a requirement that the diagnosis and care planning services be documented in the beneficiary’s medical record to aid in the coordination of care and management of other conditions.

Unfortunately, in the first year that HOPE-authorized care planning services were available, [only 1% of eligible patients received the services](#). The pending bipartisan Improving HOPE for Alzheimer’s Act requires the Centers for Medicare & Medicaid Services (CMS) to conduct education and outreach about care planning services available for individuals with Alzheimer’s disease and related dementias to physicians, physician assistants, nurse practitioners, clinical nurse specialists, and certified nurse midwives. Additionally, it requires a report to Congress on provider outreach and utilization rates, including information on any barriers Medicare beneficiaries face in accessing these services and recommendations to address those barriers.

An important concern related to Alzheimer’s care planning services is the paucity of high-quality guidelines for advance care planning (ACP) in dementia care, which are vital to providing appropriate and effective interventions and ensuring that Alzheimer’s patients have a timely opportunity to document their care wishes and to have those wishes honored.

Recommendations: The Coalition supports legislative and regulatory action to help expand access to care planning services for Alzheimer’s patients and their caregivers. Specifically, we recommend:

1. CMS should create educational materials and provide outreach regarding care planning services to physicians and non-physician practitioners with specific guidance on how to use the ACP codes in practice.
2. HHS should convene appropriate agencies under its jurisdiction to develop appropriate guidance and training for practitioners regarding effective provision of ACP for dementia patients across settings. This could include guidance related to documenting ACP discussions during the early stages of Alzheimer’s disease, when the patient may be able to express their wishes, including their preferences for care/treatment as their disease progresses.
3. For CPT code 99483 (cognitive assessment and care planning services) and other high-value CPT codes, such as chronic care management codes, we recommend that the patient co-pay be eliminated to encourage broad utilization. The Chronic Care Management Improvement Act as [introduced](#) in the House ([H.R. 3436](#)) would “remove cost-sharing responsibilities for chronic care management services under Part B of the Medicare program.” There is no companion bill in the Senate.

- **Home and Community Based Services:** The Older Americans Act focuses on delivering home and community-based programs and supports, including nutritional programs, in-home services, transportation, elder abuse prevention, legal services, and caregiver support. OAA services are targeted at older individuals who have the greatest economic and social need, have low income, are members of low-income minority groups, reside in rural areas, have limited English proficiency, or are

at risk of entering a nursing home. We are seeking feedback on how the programs are reaching individuals living with Alzheimer's and other dementias and any gaps that may exist in these services.

1. **Transportation:** To minimize burdens and distress for patients with advanced dementia, medical transport should be minimized, and the care team should come to the patient whenever possible rather than bringing the patient to the care team. Such an approach is essential for person-centered care. Particularly where a community-based workforce is in short supply, telehealth may be an effective way to conduct clinician visits without burdening patients, but current “originating site” restrictions pose a barrier.

Recommendation:

We request a waiver of site of service and geographic location requirements to allow billable telehealth visits for palliative care and other healthcare teams serving patients in home and community settings.

Concerns about Long Lengths of Stay in Hospice Care: At the time that the Medicare Hospice Benefit was created, it was expected that the program would, for the most part, serve terminally ill cancer patients. The average length of stay for patients participating in the hospice demonstration program (prior to death) was 40 days. Since the hospice benefit’s inception in 1983, there have been dramatic changes in cancer treatment and significant shifts in the types of patients that receive hospice care. Instead of cancer care, the most prevalent principal diagnoses for patients receiving hospice care today represent neurological disorders (including Alzheimer’s disease and other dementias). Cancer patients currently average 52 days on hospice care, while patients with neurological disorders average 149 days of care.⁸

While there are widespread concerns that those patients who enter hospice care in the final days of life do not reap the full benefit that hospice has to offer, there are also concerns that some patients are on service for very long lengths of time, which raises questions about whether the patient admitted for service did not meet eligibility criteria (a prognosis of six months or less if the disease runs its normal course). However, it is, as a general rule, more difficult to establish an accurate prognosis for non-cancer patients than for patients who have a principal diagnosis of terminal cancer.

⁸ MedPAC Report to Congress; 2019:http://www.medpac.gov/docs/default-source/reports/mar19_medpac_ch12_sec.pdf

Recommendations:

The hospice community does not support admission of patients onto service who are not eligible for hospice care and recognizes the appropriateness of taking steps to address inappropriate length of stay. However, experts in the field will attest that arriving at an accurate prognosis for patients with neurological conditions (including Alzheimer's disease) is much more difficult than it is for cancer. That difficulty in assessing prognosis for the patient with advanced Alzheimer's disease should not preclude that patient from accessing hospice services. Hospice services can provide care services to patients and important support to families for the patient with advanced Alzheimer's disease.

Some proposals to alter financial incentives in hospice care (including across-the-board cuts to the hospice aggregate cap or direct cuts to hospice care for patients residing in nursing facilities) are blunt instruments that could severely impact patients for whom accuracy of prognosis is a significant challenge. For this reason, we urge caution when addressing this issue.

2. Caregiver Support

As the number of individuals with Alzheimer's and related dementias increases, there is an overwhelming need for respite services so that caregivers can take a break and rest while their loved one receives safe, 24-7 care. While the benefits of family caregiving are plentiful, caregiving can take its toll, with older spousal family caregivers experiencing higher mortality rates, rates of acute and chronic conditions, and depression than non-caregivers. Respite – short-term care that offers individuals or family members temporary relief from the daily routine and stress of providing care – is a critical component to bolstering family stability and maintaining family caregiver health and well-being. Respite is a frequently requested support service among family caregivers, but 85% of family caregivers of adults receive no respite, and the percentage is similar for parents caring for their children with special needs. [Not surprisingly, high burden family caregivers \(defined as those who assist their loved one with personal care, such as getting dressed or bathing\) cite the need for respite as a high priority.](#)⁹ (page 69)

The Lifespan Respite Care Program was authorized by Congress in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201) and has been reauthorized on a continuing basis since that time. Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. Such programs reduce duplication of effort and assist in the development of respite care infrastructures at the state and local levels to support a critical element of the health care safety net – the more than 43 million family caregivers that currently provide the vast majority of our nation's long-term care, allowing individuals to remain in their communities and avoid or delay nursing home or other care placements. Lifespan Respite Care programs work to improve the delivery and quality of respite services available through the following objectives:

1. Expand and enhance respite services in the states;
2. Improve coordination and dissemination of respite services;

⁹ AARP, Caregiving in the United States, <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>

3. Streamline access to programs;
4. Fill gaps in service where necessary; and
5. Improve the overall quality of the respite services currently available.

Since 2009, Congress has appropriated approximately \$2.5 million per year to implement Lifespan Respite Programs. As of 2017, competitive grants of up to \$200,000 each were awarded to eligible agencies in 37 states and the District of Columbia.

Recommendation:

In the interest of continued support for this vital resource, the Coalition strongly encourages ongoing support for the Lifespan Respite care Program.

Improving Detection and Care:

- **Ensuring Early Detection and Diagnosis: Connecting Alzheimer’s patients with options to address symptoms, and someday, treatments and a cure, requires early detection and a diagnosis documented in an individual’s medical record. While the National Institute on Aging at NIH has validated tests to detect cognitive impairment, we understand there is wide variation on the use of these tools and other evidence-based practices. We seek feedback on how to better utilize the existing “Welcome to Medicare” initial exam and Medicare annual wellness visits to screen, detect, and diagnose Alzheimer’s. We also seek feedback on how best to incentivize detection and high-quality care.**

1. Functional Assessment

Only 50% of patients with cognitive impairment have a formal diagnosis listed in their medical record.¹⁰ Outside of hospice, home health or skilled nursing facilities, electronic health records routinely lack key information about level of cognitive impairment, functional status, ability to perform activities of daily living, and caregiver concerns. It is essential to assess cognitive and physical function and caregiver needs every time a patient with dementia receives medical care, not just when enrolled in hospice, skilled nursing or home health benefits, but also when seen in the hospital, outpatient clinic or home.

Recommendation:

To address patient and caregiver needs and coordinate care across programs, cognitive and physical function assessments should be built into all electronic health records and available to clinicians in any care setting.

2. **Inadequate clinician training:** Many clinicians who care for older adults lack training in the recognition and management of signs and symptoms of dementia and essential palliative care skills, such as symptom management, shared decision-making and interdisciplinary team care. [Workforce shortages in specialty palliative care](#) are projected to worsen over the next several decades. We need both to train more specialist clinicians and to increase the essential palliative care skills of non-specialists who care for people with serious illness,

¹⁰ https://act.alz.org/site/DocServer/Policy_Brief_-_Early_Detection_and_Diagnosis_Brief__Assn.pdf?docID=53576

including dementia.

Recommendations:

The Coalition supports the Palliative Care and Hospice Education and Training Act (PCHETA), passed in the House as [H.R. 647](#) and introduced in the Senate as [S. 2080](#). The bill has broad bipartisan support. We provide a [summary of the bill](#) for your information. We ask that the Senate move PCHETA forward and pass it as currently written and passed in the House.

As there are NO Medicare-supported residency slots for hospice and palliative medicine training due to the BBA cap imposed in 1997, we also call for [Graduate Medical Education \(GME\) finance reform](#), specifically to increase funding for residency slots that can be used to train physicians to be palliative medicine specialists.

- 3. Interdisciplinary team approach to care:** As outlined in the NCP Clinical Practice Guidelines for Quality Palliative Care, 4th ed,¹¹ beneficiaries with Alzheimer’s Disease and related dementias benefit from an interdisciplinary team approach based on a comprehensive assessment of physical, psychological, social, spiritual, cultural and practical needs.

Recommendation:

Payment policies should support interdisciplinary team care for these patients regardless of setting of care or payment program.

- 4. Appointment length:** Longer appointments are needed to assess and manage patients with Alzheimer’s and related dementias, and an interdisciplinary approach is essential. While delivering a diagnosis of dementia is the responsibility of the physician or advanced practice provider, a nurse or social worker may be the best clinician to assess caregiver needs, engage in disease education, or deliver emotional support.

Recommendation:

Reflect the importance of the longer appointment time for dementia-related diagnoses in the coding and RVU values assigned.

- 5. Care transitions:** As dementia progresses, transitions between care settings and clinician teams are common and fraught with problems, including communication breakdown, medication errors, disrupted treatment plans, neglected goals of care, and increased patient and caregiver distress. Transitions in care triggered by uncertain life expectancy or longer stays on service are particularly problematic and may result in care disruptions, distress, unnecessary hospital or emergency

¹¹ Clinical Practice Guidelines for Quality Palliative Care: 2018: https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf

department visits, and other unintended consequences for people with dementia and their caregivers.

Whether care is provided under established benefits, such as hospice, skilled nursing and home health, or under alternative payment model demonstrations, such as the Primary Care First Serious Illness Population Model, special attention should be focused on analyzing the experience and outcomes of care for this vulnerable population, particularly when transitions in care may be driven by payment policy (e.g. 6-month life expectancy to remain eligible for hospice or 8-month average length of stay threshold measure in the Serious Illness Population Model), rather than changing patient and caregiver needs.

Prognosis is inexact in late-stage dementia, and many patients survive for years despite severe functional impairments requiring total care. Payment policies that are based on life expectancy or impose arbitrary limits to length of service can force disruptive care transitions that do not meet the needs of patients and caregivers.

Recommendation:

Care for dementia patients should be driven by their needs, not by arbitrary payment policies. Careful consideration should be given to changes in regulations to allow patients with Alzheimer’s and related dementias to avoid transitions in care that are triggered by regulations or payment policy, rather than patient need. If unintended negative consequences are identified, new eligibility and payment policies should be developed and carefully tested.

- 6. Quality measure development:** Medicare quality reporting programs vary by setting of care, and there are few measures endorsed for accountability that are cross-cutting and meaningful to people living with dementia and their caregivers. Although a limited set of quality measures are reported under certain Medicare programs, such as the Hospice Quality Reporting Program, there are no meaningful quality measures reported for patients with Alzheimer’s and related dementias that cut across the entire range of programs in which they may be enrolled.

Recommendations:

We recommend expanded investment in the development of quality measures that address the outcomes and experience of care that matter to patients with Alzheimer’s and related dementias and their caregivers.

We further recommend harmonization of these measures and broad implementation across all programs that serve this population, so that patients and families know what to expect and clinicians know that they will be held to the same high standard of care no matter which program happens to be in effect.

Protecting Vulnerable Patients:

- **Preventing Abuse:** While the vast majority of nursing homes, home health agencies, and hospices have dedicated leadership and staff committed to the health, wellness, and dignity of their residents, we cannot ignore reports of patient abuse. The subcommittee is requesting policy recommendations that improve the oversight of facilities and providers with poor records of patient abuse, neglect, and safety without imposing undue burden on those that provide high quality care.

The Coalition has been actively involved in discussions with both the Senate Finance Committee and the House Ways and Means Committee on hospice program integrity proposals. [S. 2807](#) and [H.R. 5821](#) will provide State survey agencies and accreditation organizations with additional remedies for poor performing hospices, as well as improve surveyor education and competency, develop a special focus program to provide additional enforcement of hospice regulatory requirements, and recommend a GAO study to study the effectiveness of civil monetary penalties.

Recommendations:

We specifically support the following language from these bills:

1. **Accreditation organization surveys made public:** The Secretary of Health and Human Services (“the Secretary”) is authorized to disclose accreditation surveys to the same extent as they’re currently authorized with respect to home health agency accreditation surveys.
2. **Survey frequency:** The Coalition supports survey frequency of every 36 months, with more frequent surveys for hospices that are found to be “poor performers” and for new hospices. For these hospices, surveys could be done no less frequently than once every 12 months until no serious deficiencies are found after two completed surveys, at which point they would revert to the routine 36-month survey cycle.
3. **Newly certified hospices:** After the date of enactment, any newly certified hospice program is subject to a standard survey within 12 months of initial certification.
4. **Issues of immediate jeopardy:** The Secretary shall take immediate action to remove the jeopardy and correct the deficiencies through an alternative remedy or terminate the certification of the program.
5. **Alternative sanctions/remedies:** Additional remedies could include:
 - a. **Suspension of all or part of the payments** to which a hospice program would otherwise be entitled.
 - b. **The appointment of temporary management** to oversee the operation of the hospice program and to protect and assure the health and safety of the individuals under the care of the program while improvements are made.
6. **Special focus program:** The Secretary shall conduct a special focus program for enforcement of requirements for hospice programs that the Secretary has identified as having substantially failed to meet applicable requirements of this Act.
7. **Periodic surveys under the special focus program:** Under such special focus program, the Secretary shall conduct surveys of each poor performing hospice program in the **special focus program not less than once every 6 months.**
8. **Increasing payment reductions for the absence of quality data reporting:** For fiscal year 2021 and each subsequent fiscal year, the payment reduction for a hospice that does meet the threshold reporting requirement for quality reporting would increase from 2 percentage points to 4 percentage points.
9. **GAO report on civil monetary penalties:** Not later than 36 months after the date of the enactment of this Act, the Comptroller General of the United States shall submit a report containing an analysis of the effects of civil monetary penalties, the frequency of their use and their impact on access to, and quality of, care furnished by hospice programs.

Conclusion

Thank you very much for the opportunity to provide these comprehensive policy recommendations for expanding access and availability of palliative care to patients with Alzheimer's and related dementias. We believe our recommendations regarding specific legislative and regulatory changes to Medicare, Medicaid and the hospice benefit would improve quality of care and quality of life for this vulnerable population, as well as their family/caregivers.

Representatives of our Coalition would be pleased to meet with the Senate Finance Committee to discuss these issues in greater detail. Please contact Amy Melnick, Executive Director, at amym@nationalcoalitionhpc.org or 202.306.3590 to arrange a meeting or conference call with experts from our member organizations.

Sincerely,

Members of the Coalition

American Academy of Hospice and Palliative Medicine
Association of Professional Chaplains
Center to Advance Palliative Care
Health Care Chaplaincy Network
Hospice and Palliative Nurses Association
National Association of Home Care and Hospice
National Hospice and Palliative Care Organization
National Palliative Care Research Center
Physicians Assistants in Hospice and Palliative Medicine
Social Work Hospice and Palliative Care Network
Society of Pain and Palliative Care Pharmacists
Supportive Care Coalition

Appendix
Families Share Their Experiences
with a Parent with Alzheimer's on Hospice

Feeling Abandoned by Hospice: A Plea for Reform

By J. Randall Curtis

March 2020

I've been working in the palliative care field since before we called it "palliative care." When I was starting my career, palliative care was mostly limited to end-of-life. Thankfully, since then, we've realized that limiting this type of service to "end-of-life" meant missing opportunities to provide support for patients who had serious unmet medical needs but weren't necessarily at death's door.

As a researcher, I've looked at understanding palliative care, particularly how it can be improved to deliver the best quality care to patients and their families. This desire for understanding drove me to build the Cambia Palliative Care Center of Excellence, a center devoted to developing, promoting, and implementing evidence-based care.

But despite my extensive knowledge of palliative care, I've personally experienced the frustration when burdensome regulations interfere with access to this important service. Time and time again, I've had to grapple with the consequences of our local hospice kicking my own mother off of their list of patients – what's known in the hospice sector as a "live discharge."

My mother is an amazing woman. Born and raised in a small town in Connecticut, she developed polio at the age of 15 and stayed in the hospital for two years to receive treatment. The illness left her wheelchair-bound for the rest of her life, deprived forever of the use of her legs. While my grandparents thought she'd live with them into adulthood, my mother's life took yet another unexpected turn. She fell in love with my father, got married, gave birth to two children, and raised us. Beyond her domestic accomplishments, she also completed her college degree, worked full time and even became an accomplished writer. She didn't slow down until her 80s and then only because of progressive post-polio syndrome and dementia.

When she first became bed-bound, she required the support of a non-invasive ventilator and a whole host of other care related needs. This was too much for my father, her primary caregiver, to keep her at home. We arranged to have her admitted to a nearby nursing home, and, because doctors believed her prognosis from her respiratory illness was six months or less, to a hospice program.

Hospice provided her care through friendly visits and easy access to pain medications to ensure she was comfortable. More importantly, hospice provided support for my father by giving him occasional respite and peace of mind as my mother continued to grow increasingly confused and anxious. Over the next six months, my mother's dementia advanced and she became less active, eating less, and continuing to lose weight. The extreme weight loss meant her breathing requirements dropped too, and she no longer needed any ventilator support. Throughout this time, her memory worsened and her sense of anxiety grew.

After six months of care, the hospice program began to talk about "live discharge" because she didn't need the support from the ventilator anymore. To be clear, this was not because she was better; she was actually worse – but being on the ventilator had helped her qualify for hospice and without it she was disenrolled. Off of hospice, she continued to decline and her weight continued to drop to the point that she once again qualified for hospice. After re-enrolling, her weight stabilized, and she was again discharged given the lack of objective decline in her condition.

This on-again, off-again, yo-yo policy has been an enormous source of frustration for my entire family. Yes, without hospice my mother still has care and we are able to patch together most of what we need through many hours of family involvement and the support of her nursing facility. But being on hospice was a great sense of support and relief for my mother, father, and the rest of my family. Being denied those services – twice – through a bureaucratic rule that requires objective criteria of continued worsening feels – well – bureaucratic. And wrong.

A recent systematic review of research on “hospice live discharges” suggests that our experience is not unique.¹² All over the country, patients and families are feeling abandoned by their hospice programs when they are forced to go through “live discharges.”

I have no doubt that many hospice providers share the sense of frustration felt by many of the patients and family members who experience a live discharge from hospice. Our hospice provider told me that they didn’t want to discharge my mother, but felt they had to. That didn’t make me feel better.

As a leader in the field of palliative care and as a son, this part of the system for supporting dying patients and their family members feels broken. Hospice rules need to be reformed so that patients and families with illnesses that make it difficult to prognosticate – dementia, for example – can continue to get needed care without being discharged. When the six-month prognosis rule was established, most hospice patients died of cancer and cancer therapies were much less effective. The time has come to update the eligibility rules for hospice to mirror the heterogenous needs of today’s hospice patients and families. Rather than focusing on months, hospice length of stay, or live discharge, we should update hospice rules to focus on care needs and to assure continued access to those who need person-centered, interdisciplinary care.

I do this work for a living and yet I still find the status quo confusing and frustrating. More should be done by patient advocates and policymakers to reform this system so families, like mine, can depend on the person-centered care they so desire for their loved ones. These efforts won’t be in time to help my mother, but I hope we can get them in place soon so that other families don’t have to go through this experience as they care for their dying loved ones.

Note: Dr. Curtis’ mother died in mid-January, 2020. He was able to get her back on hospice for the 3rd time Thanksgiving weekend and she had 6 weeks back on hospice before she died. It was incredibly helpful to have her back on hospice.

J. Randall Curtis, M.D., M.P.H., is a board-certified physician at Harborview Medical Center, director of the Cambia Palliative Care Center of Excellence at UW Medicine and the UW’s A. Bruce Montgomery-American Lung Association Endowed Chair in Pulmonary and Critical Care Medicine.

¹² Wu S, Volker DL. Live Discharge From Hospice: A Systematic Review. *J Hosp Palliat Nurs* 2019;21:482-8

[The Washington Post \(05/05/18\)](#)

[Health & Science](#)

At 100, my mom had dementia and needed hospice care. Getting it was nearly impossible.

By Jeanne Erdmann

May 5, 2018 at 9:00 a.m. EDT

When my mother prayed — when she remembered what prayer was — she asked every saint to please let her die in her sleep. In late 2016, my mom died that way, in her own bed, one week past her 101st birthday. One of my sisters and I were curled around her, asleep ourselves.

My mom's death was perfect, and hospice helped. But her dementia made enrolling her and keeping her in hospice nearly impossible. She died during her second stint in hospice.

The year she died, I had reached out to a hospice and palliative-care agency because my mom seemed to be heading downhill fast.

A gerontologist had diagnosed my mom with late-stage dementia and encouraged us to place her in nursing care. My mom needed help with dressing and using the bathroom. She wasn't bedridden, but bone-crunching osteoarthritis and worsening cognitive issues kept her marooned in a chair. She could feed herself once a plate of food was set in front of her. She spoke, but not a lot, unless she was in full-blown agitation.

By then, one of my sisters and I had switched caregiver roles. A stint with pneumonia at Christmas in 2014 had left my mom too weak to remain in one of my second-floor bedrooms. She moved to my sister's, where she spent her days in a chair near her bed, moving only when my sister walked her a few steps to the bathroom. Many days, she would be alarmed if my sister left the room.

We kept our mom as active as possible, even bringing in a personal trainer. Eventually, though, we started taking her to the emergency room a lot — when she was suddenly lethargic or covered in red welts after she slid the two feet from her bed to the carpeted floor. We would call her primary-care doctor and then wait all day for a response. By then, my sister, in full-blown panic, would take her to the ER.

In early 2016, my mom grew even frailer. Hospice made sense. I read the Medicare guidelines and thought she might qualify. From the start, we hit a snag. A hospice intake nurse told us that my mom's dementia alone was not enough to qualify her — she wasn't bedridden, and she could speak.

The Medicare reimbursement schedule is tied to predicting when a person is within six months of death. People can linger in late-stage dementia for years. There are no scans, blood tests or other scientific ways to predict when a person with dementia will die. Making matters worse, in 2013 Medicare removed "failure to thrive" — one of the hallmarks of late-stage dementia and what some physicians call frailty — and debility as primary diagnoses for hospice entry. But people with dementia decline over years and years, and frailty is part of that decline.

"Whatever the disease, whether it's dementia or cancer or ALS, doctors have to have some experience in seeing how end-stage progresses, and then look at that person to see what the medical conditions are, and make a decision if they think it's within six months of life," said Beth Kallmyer, a vice president of the Alzheimer's Association.

People don't access hospice until the very end of life. Fifty percent have hospice care for fewer than 18 days, and 35 percent have a length of stay of seven days or less. "That's really frustrating," said Judi Lund Person, a vice president at the National Hospice and Palliative Care Organization.

Hospice providers would like to do more, Lund explained: "Often after a patient's death, the family will report in surveys about the care received that 'they wish they had known about hospice sooner,' because the services that a hospice can provide have great benefit for the patient and their family if they access hospice services for two months or more."

The Medicare Care Choices Model, or MCCM, might serve as a bridge to hospice care. A pilot program, MCCM offers certain chronically ill patients 24/7 access to supportive care services provided by hospice agencies, Lund Person said. Such services might be a phone call from a hospice nurse, a chaplain or a social worker, or a home visit.

"Patients still have their regular doctors and are not enrolled in hospice, but they are seriously ill," Lund Person said. "These may be people who qualify for hospice but may not be mentally ready to enter the program. They would be able to get supportive services and get comfortable with what's going on in their disease process, and get help on the medical side and also help on the social side."

To be eligible, patients must be enrolled in Medicare and meet hospice requirements but not be enrolled in hospice. The conditions covered are advanced cancers, congestive heart failure, chronic obstructive pulmonary disease and HIV/AIDS. Dementia is not covered.

MCCM, which aims to improve quality of life and reduce costs, started with 30 hospice programs in 2016. The second cohort of patients began receiving care this year from 140 programs.

A blood test taken during one of the ER visits ended up qualifying my mom for hospice with a diagnosis of congestive heart failure. Hospice was our miracle. For the next six months, weekly visits from nurses and aides gave my sister respite and helped us stay ahead of skin and bowel issues that had also brought us to ERs. A social worker and a chaplain provided emotional support. When any health issue came up, my sister called a 24/7 nursing hotline. Trips to the ER ended.

Once six months were up, though, hospice ended. Mom was not recertified because she wasn't declining quickly enough. Her diagnosis hadn't changed, her dementia had certainly progressed, and she was much more frail than when she was enrolled in hospice.

Leaving hospice left my sister heartbroken and exhausted. Hospice, after all, is wraparound care designed for patients and their families. Nothing in the medical system replicates hospice services. There are no alternatives.

Stephanie Wladkowski, an assistant professor of social work at Eastern Michigan University, [recently started looking into](#) "live discharges." She learned that leaving hospice can be traumatic for caregivers. To me, that wasn't surprising. Caregivers inhabit a world of the unknown, of second-guessing, of rarely knowing what to do. "I fear that hospice agencies have become more concerned with these diagnoses, and therefore do not enroll or admit people onto hospice if they have concerns of them remaining enrolled," Wladkowski said.

Enrolling patients in hospice, dis-enrolling them and perhaps re-enrolling them once death is obviously imminent does require burdensome documentation, but hospice means so much more than a bulging two-ring binder. "That is psychologically crazy, and financially crazy for families, and it's a bigger battle than just a policy battle," said Debbie Parker-Oliver, a professor of family medicine at the University of Missouri School of Medicine.

Hospice enrollment has perhaps the [most stringent regulations](#) for Medicare reimbursement in the health-care industry, said Timothy Ihrig, a palliative-care physician in Des Moines and the chief medical officer at Crossroads Hospice, the agency we used.

The change was necessary and recommended by physicians and hospice nurses, explained Zinnia Harrison, a vice president at the National Hospice and Palliative Care Organization. Harrison served at the Centers for Medicare and Medicaid Services (CMS) as division director in home health and hospice for payment policy. "We wanted a better picture of what those diagnoses would look like in the population, because frailty is most often a symptom of something else," she said.

Ihrig would rather that CMS develop a mechanism for penalizing people who don't follow the rules than discharge people who can't care for themselves. "There needs to be a more realistic conversation about admission criteria for dementia," said Ihrig, who also helped care for his mom.

Even though Ihrig's mom, like mine, had late-stage dementia, she qualified for hospice because of her chronic obstructive pulmonary disease. Here's the kicker: Ihrig's mom was dis-enrolled after 120 days for not declining quickly enough. Ihrig fought to keep her in hospice but lost.

"I tried to make the case, knowing exactly that this is a progressive, irreversible, terminal disease, and she's not going to get better," Ihrig recalled. "This was quite an emotional journey for me even though that's the space I've worked in my entire career." Three weeks later, his mom died, again enrolled in hospice.

My family's experience mirrored that of Ihrig's. When my mom was visiting my house about five weeks after her discharge, she woke one morning and shook her head at toast and sweet tea. She wouldn't move from the chair beside her bed. When my husband tried to lift her, she went limp. I called the hospice agency, and she was re-enrolled. She died two weeks later. We were, and still are, at peace, because my mom died so beautifully. Not everyone is so lucky.

Erdmann is a freelance health and science writer in Wentzville, Mo. This article was written with the support of a journalism fellowship from New America Media, the Gerontological Society of America and the John A. Hartford Foundation.